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<b>13. Abstract (Maximum 200 Words) (abstract should contain no proprietary or confidential information)</b> Prostate cancer continues to rise in the United States and at a faster rate for African American men than for White men, for reasons that are not clearly understood. This study developed a prostate screening tracking system for men who participated in free screening in an urban setting. It provided follow-up for men with abnormal Prostate Specific Antigen Tests (PSA's) and Digital Rectal Examinations (DRE's) who attended annual mass screening clinics. The overall goal was to create a database of the men who seek prostate cancer screening, including both the PSA and DRE, and accept follow-up services. The study organized screening data on 792 men who received free screening in 1998 and 1999. Follow-up data is included on men who had abnormal test results in the 1998-2000 screening clinics. The goal was to determine if they consulted a health care provider and made follow-up visits. The database for this study was developed from screening questionnaires, telephone interviews, and focus group interviews. Characteristics of men who attend mass screening clinics were determined. This study included six community-based focus groups to ascertain African American men's concerns about prostate cancer screening.				
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## INTRODUCTION

This study was conducted to determine who comes to free mass prostate cancer screening and why do they come, how men with abnormal screening results make decisions about follow-up, and African American men's concerns and attitudes about prostate cancer screening. This study evolved from a free prostate cancer screening day, which has been sponsored annually for 10 years at Duke University Medical Center (DUMC), Durham, North Carolina. The free screening clinics are offered once a year at two sites. One clinic is located in the Urology Clinic at Duke University Medical Center. A second clinic is set up at Lincoln Community Health Center, a clinic that provides care to many uninsured and to many African American residents of Durham. A tracking system was designed with a structured follow-up mechanism for abnormal Prostate Specific Antigens (PSA) and Digital Rectal Examinations (DRE) for men who attended the free screening clinics.

## BODY

In the United States, prostate cancer has become the second most commonly diagnosed cancer in men after skin cancer, and the second most common cause of male cancer death exceeded only by lung cancer. It accounts for almost as many deaths among men as breast cancer among women (ACS, 2000; National Cancer Institute, 2000). Prostate cancer is the fourth most commonly diagnosed cancer in men worldwide. However, the mortality from prostate cancer is generally highest in Western countries than in developing countries of the Middle East or Asia.

It is estimated that in 2001 in the United States 180,400 new cases of prostate cancer will be diagnosed and 31,900 deaths will occur (ACS, 2000; Landis, Murray, Bolder, 1999). However, prostate cancer is a disease in which the incidence and mortality rates vary significantly according to race and ethnicity. Mortality among African American men from prostate cancer is among the highest in the world with a rate of 53.7 per 100,000.

Within the United States the differences in prostate cancer incidence and mortality are startling. The incidence of prostate cancer in African American men is estimated to be as much as 66% higher than among age-matched White men (Eyre, 1997). Between 1990 and 1995, the incidence rate among African American men was highest at 224.3 per 100,000 compared to White men at 150.3; Hispanic, 104.4; Asian/Pacific Islander, 82.2; and American Indian, 46.4. The mortality rate for this disease is also dramatically two-fold higher among African American men versus the highest mortality rate of other racial and ethnic groups (Bozeman, et al., 2000; Powell, et al., 2000).

Despite its prevalence, the natural history of prostate cancer is remarkably heterogeneous. In many men, the cancer progresses slowly, resulting in moderately or poorly differentiated tumors that remain localized to the prostate gland. Although potentially life threatening, such cancers are often curable. In other men, however, tumor growth is rapid and can spread beyond the confines of the prostate, usually to the bone. Early diagnosis is essential because the majority of prostate cancer diagnosed by the prostate specific antigen or PSA (85%-90%) is rapid growing and, if left untreated, would most likely progress. (Elhilali, 2000; Fleshner, Rakovitch, & Klotz, 2000; Hankey, et al., 1999). In such cases, the cancer is not curable, and long-term survival is considerable diminished. Strategies for managing prostate cancer, therefore, have been aimed at early detection and local treatment of the cancer (Anonymous, 2000). With early detection through screening and timely treatment, nine out of ten men will survive a minimum of five years. However, with late diagnoses, only three of ten men will have a 5-year minimum survival rate (Tingen & Weinrich, 1998).

The conceptual framework for this study is based on the Health Belief model (HBM; Rosenstock, 1988). The HBM is one of the most widely recognized conceptual frameworks of health behavior. The premise underlying the model is that individuals fear the threat of a health problem. A person's motivation and confidence to activate readiness for action are based on one's perception of the degree of the perceived threat. However, perceived barriers and benefits mediate those actions.

Relatively little is known about the characteristics of men who attend free prostate screening clinics, what motivates them to attend the clinic, and how they make decisions to follow-up when they have abnormal findings from the screening. In the present study, three major research activities were conducted. First, a database of annual screening participants was developed. From the database, the

characteristics of men who voluntarily participated in free prostate cancer screening were examined. Second, participants with abnormal findings on screening were telephoned to determine if they sought follow-up care and how they made their decisions to follow-up on those results. Third, focus groups were used to hear first-hand the concerns and attitudes of African American men about prostate cancer screening and to increase African American men's awareness about early detection of the disease. Findings are discussed in this report.

### Background Information on the Free Mass Screening Clinics

The sponsorship of the free mass prostate screening on which this study was based was not part of this study. However, data from the clinics was provided for this study. Free mass prostate screening in Durham is longstanding. Screening was began in 1992 by an urologist at Duke University Medical Center who specializes in diseases of the prostate, primarily prostate cancer diagnosis and management. Duke University Medical Center is a Research I institution located in Durham. Free prostate cancer screening has been offered annually to men 40 years and older, regardless of racial background or ability to pay. The free clinic was conducted in the fall of each year to coincide with Prostate Cancer Awareness Week. In 1997, an additional clinic was added at Lincoln Community Health Center, which is centrally located in a primarily African American residential area of Durham's inner city. The sponsor of the free clinics recognized that few African American men participated in the free screening day. The Lincoln site was added to attract African American men to screening. Historically, this comprehensive health center primarily has served low-income African American families.

Information publicizing the free clinics in the Durham community has varied. In 1998, the Duke University Medical Center public relations department designed and distributed flyers in the community in various public agencies, churches, medical clinics, physician offices, and public clinics. Public relations also produced newspaper (the main city newspaper and the local African American newspaper), television, and radio public service announcements about the free clinics. A mailing list was purchased that contained approximately 25,000 names and addresses of men in Durham who were 40 years of age and older and a flyer announcing the free clinics was mailed to each individual on the list. In 1999, a similar procedure was conducted to provide community awareness about the free clinics. In the year 2000, the DUMC public relations department was eliminated. The only form of publicity was the use of a purchased mailing list to target men in Durham.

The four-hour clinics were conducted on a weekend day at both clinics. At Lincoln Health Center, the clinic was conducted in the primary care clinic. Urology attending physicians from Duke University Medical Center conducted examinations at both clinics. Also at Lincoln, Lincoln's internal medicine physicians conducted examinations in addition to the urologists from Duke. PSA samples were collected by laboratory staff at either clinic and processed in the usual manner for PSA samples at the respective facilities. At both clinics, staff and individuals from the community volunteered to generally assist participants, assist participants with completing forms, and to facilitate orderliness and ease in moving through the stations of the screening clinic. Participants were screened on a first-come, first-served basis. Upon registration, participants voluntarily read and signed a consent form that gave information about prostate cancer, and what screening involved. Participation required their signature along with a witness signature. Participants indicated on the consent form (Appendix A) if they could be telephoned regarding any abnormal findings found on screening. Prior to participating in the screening activities, participants completed a Prostate Cancer Screening Questionnaire (Appendix B) and a Prostate Health



Survey (Appendix C). Requested information on the forms included participant demographic characteristics, family and medical history related to prostate and breast cancer, urinary symptoms, and why the individual sought screening.

Men waited their turn for screening in clinic waiting rooms and hallways. Results of the DRE, either normal or abnormal, were recorded by the physician in a Digital Rectal Exam Results section on the reverse side of Prostate Cancer Screening Questionnaire. Whether the exam was normal or abnormal, the man was verbally informed of the results, and given a tear-off Patient Information section of the questionnaire with the results. If the exam indicated that the prostate was found to be abnormal indicating a need for further follow up by a physician, the man was instructed to see his physician as soon as possible. When Bilateral Prostatic Hypertrophy (BPH) was found on the DRE, the physician discussed information about this condition directly with the participant, and gave verbal advice for any further care. When the screening was completed, each participant was provided light refreshments and an information packet with brochures about prostate cancer.

PSA tests were processed and the results were sent by letter to the patient within three months. The letter that stated that their DRE and PSA results were either normal or abnormal and the numerical value of the PSA was stated in the letter. The letter was mailed to the participant's address that he wrote on the questionnaires at the time of screening. If either the DRE or PSA showed abnormal findings, the participant was again instructed in the letter to seek follow up with a physician. Following the clinic, a list of the names of the participants and their PSA values were made, and placed in storage with the questionnaires. No medical records were made. Copies of the consent form, questionnaires, and PSA list all were provided to the study investigator.

## METHODS

### Sample

This study focused on African American men in Durham, North Carolina, a small urban city. During the time period that this study took place, Durham had an overall population of 197,711, and was 40% non-White. The non-White population is largely African American. The African American rate for prostate cancer is higher among African American men. From 1993-97, the incidence rate for prostate cancer for Durham's African American males was equal to the African American rate for the United States at 208 per 100,000 (224.12%), compared to a rate of 294 per 100,000 (123.64%) for Durham's White males. The North Carolina overall state rate during this five-year period (1993-97) was 124.07% for White males, and 199.71% for Black males (NC Center for Health and Environmental Statistics, 2001).

Data used in the present study were collected from participants who volunteered for free mass prostate cancer screening at either Duke University Medical Center or Lincoln Community Health Center. Participants attended either of two screening sites conducted during September 1998, and October 1999. In addition, participants who were screened at mass screening in September 2000 were included in the follow up data if they had abnormal DRE and PSA findings.

In 1998 and 1999, 792 men were screened at a free mass prostate screening at the two sites. Four hundred eighty-five men were screened in 1998 and 419 men were screened in 1999. A total of 904

screening visits were made<sup>1</sup>. Further description of the sample is detailed in the Results section of this report. The total number of screening clinic visits decreased from year 1998 to 1999, 485 versus 419 in each year respectively. A calculation of duplicate participants in 1999 indicated that 110 men who were seen in 1998 also returned for screening in 1999. From this study data, we cannot measure if men who did not return for screening sought screening elsewhere, such as from their personal health care provider or an urology specialist.

## Materials

Screening Database. To create the screening database, data from the Prostate Cancer Screening Questionnaire and the Prostate Health Survey were furnished to the principal investigator by the mass screening DUMC free clinic coordinators. The data were coded and entered into an SPSS (10.0) systems file. Data entered into the database included the following: a database individual identification number assigned to each record, the identification number assigned by the clinic, the participants' name, address, telephone number, date of birth, age in years at the time of the screening, self-reported race, type of work<sup>2</sup>, employment status, highest level of education attained, reason for seeking screening, whether the participant had a regular health care provider, the last time the participant saw a health care provider, whether the participant had a relative or close friend who has had prostate cancer, and the participant's permission to follow up by phone if his screening results were abnormal. The code book for the database is presented in Appendix D.

Follow-up Telephone Interview Protocol. Using a semi-structured interview protocol, follow-up telephone calls were conducted to contact participant's who had received abnormal screening results and to discuss whether and why the participant chose to follow-up on his abnormal screening results. Appendix E displays the Follow-Up Telephone Interview Protocol script.

## Procedure

Approval for this study was granted by the United States Department of Defense, and the Duke University Medical Center Institutional Review Board. This study examined clinic data from free screening clinics that were conducted during the Fall of 1998 and 1999 at two screening sites. In addition, year 2000 follow-up data on those men with abnormal results were included for this study. All data collection instruments, consent forms and other materials used in this study were given to the principal investigator approximately 12 weeks after the screening clinics and subsequently placed in locked file storage in the investigator's office. Trained research assistants coded and entered the data into the database.

A list of screening participants with abnormal PSA tests and DRE exams was provided to the investigator by the mass screening clinic coordinators. In 1998, telephone calls were attempted at a six-month interval to each of the participants who had either an abnormal DRE, and/or elevated PSA. Over a three-week interval on random days and various times, at least six attempts were made to reach participants. If another household member was reached and could suggest a better time to reach the participant, the participant was called back at that time. Research assistants noted that several men who had not gone for follow-up care indicated that they had plans to see a physician in upcoming months.

<sup>1</sup> This number includes 110 participants who were screened both years.

<sup>2</sup> Employment descriptions were taken from the questionnaires and categorized according to the Department of Labor job classifications (Dictionary of Occupational Titles, 1991, Department of Labor).

Once the study began, an attempt was made to contact men from the 1998 list of participants who could not be contacted initially. Contact to almost every one was unsuccessful due to telephone numbers changes or they could not recall over the 22 months since their screening visit, if they had discussed their results with a physician. For the 1999 follow-up procedures, the interval at which the follow-up contact was initiated was extended to ten months. The ten-month interval was based on the assumption that within that period of time, even in a very busy or large clinical practice, a man who intended to follow-up would have been able to get an appointment with his health care provider or an urologist. Identical procedures were followed as described for 1999 for follow-up phone calls in 2000. Each participant's response in the telephone interview about his failing to seek further medical advice was summarized, categorized by the theme of his discussion, and entered into the study database.

#### Data Analytic Strategy

Frequencies, means, and standard deviations were used to examine the distribution of participant's responses in each category. T-tests were used to examine differences between groups of participants. All analyses were conducted using SPSS (10.0).

Because the data were mostly self-report data, some participants chose not to report information that they thought was too personal or too revealing (e.g., date of birth, age, race, education, etc.). Missing data was considered missing at random. Therefore, analyses used the valid sample size excluding missing data.

### RESULTS

#### Demographic Characteristics of Free Screening Participants

Overall, 792 men were screened at a free mass prostate screening held at two sites in 1998 and 1999. The average age of the men screened was 58.74 years (s.d.=11.76), with a range of 25 to 99 years of age. There was a significant difference in age at screening between African American and White men ( $t=-8.77$ ,  $p<.001$ ). African American men were significantly younger at screening than White men were (54.80 years versus 62.22 years, respectively). Among the men screened in both 1998 and in 1999, African American men were significantly younger at screening than White men ( $t=-6.81$ ,  $p<.001$ ;  $t=-6.48$ ,  $p<.001$ , respectively). The demographic characteristics of all men who participated in the mass screening are presented in Table 1. Tables 2 and 3 present the demographic characteristics of the men screened in 1998 and 1999, respectively.

Of the men who reported their race, more than 45% (346/765) of the men screened were African American, 52.4% (401/765) were White, and 2.4% (18 of 765) were other racial and ethnic groups. Specifically, in 1998, 231 White men (50.50 %), 215 African American/Black men (47.30 %), and 18 men of other races (2.20%) were screened. In 1999, 419 men were screened: 231 White men (57.00%), 166 African American/Black (41.00 %), and 8 men of other races (2%). The demographic characteristics of all African American and White men screened are presented in Table 4. The demographic characteristics of African American and White men are presented separately by year screened in Tables 5 and 6.

Of the total sample, slightly more than half of the men (422 of 744) reported that they were still employed. Of those not employed, the majority was retired. The majority of the screening participants

reported having attained a high school diploma, having a family doctor, and having visited a doctor for health within 12 months of the screening.

Demographic predictors for participation in free prostate cancer screening were race, age, employment, education, and use of health care (having a family doctor or visited a doctor). By racial breakdown, African men were more likely to be less well educated and employed in non-professional jobs. African American men were equally likely to seek free screening at either screening site. Approximately 53.8% of African American men who participated in screening (1998 and 1999) screened at Lincoln Community Health Center, whereas 46.2% screened at Duke. Of the two hundred sixty-eight screenings that took place at Lincoln, 18.7% of the men screened were White, 76.1% were African American, and 5.2% were from other racial backgrounds.

White men, however, primarily sought screening at the free clinic offered at Duke University Medical Center. Approximately 89% of White men screened at Duke, while 10.9% screened at Lincoln. Of the 618 total screenings that took place at Duke, two-thirds were of the men screened were White, 28.3% were African American, and the remaining men were of other racial backgrounds.

1998 and 1999 screening participants were primarily older men, better well educated, and in upper levels of employment. Thirty-four percent were in professional careers while 30% were in middle level management; and 19% were in industry and trade careers. The remaining did not indicate their types of employment. These findings showed a higher level of education and employment than found in other studies of mass screening (Barber, et al, 1998; Weinrich, 1998).

Three hundred sixty-seven men (47.5%) reported having a relative or close friend who had or has prostate cancer. Roughly half of White men (202 of 392) reported having a relative who had or has prostate cancer. Similarly, 43.7% of African American men (150 of 343) reported having a friend or relative with prostate cancer.

At least 525 men (68.4%) men indicated that they had used health care. This item was not specific to having been screened for prostate cancer. Of the total number of men screened in the study, approximately 68% had a regular family doctor and reported visiting a doctor within the past two years.. For African American men, 209 (62.0%) had a family doctor. Almost 75% of White men had a family doctor (331 of 395 men). The majority of the men screened also reported visiting a doctor for health within 12 months of the screening. 83.8% of White men and 87.6% of African American men reported having visited a doctor within two years of the screening.

#### Motivating Factors to Attend the Free Clinic

Among the study participants, motivating factors to seek screening included encouragement by a spouse or loved one, early detection, peace of mind, to preserve health, and 47.5% had a relative or friend affected by prostate cancer. The finding 'to preserve health' is consistent in other studies that show across the board, that African American men are concerned about their general health and general health maintenance (Scroggins & Bartley, 1999).

### Follow-up Examinations of Abnormal findings

Background research for this project did not find any examples in the scientific research literature regarding intend to follow-up for men who had participated in mass screening for prostate cancer. One hundred percent of the men who were reached consented to the follow up interview. One hundred eighty three participants had either (or both) an abnormal prostate or elevated PSA. The number of abnormal tests was 74, 39, and 70 in 1998, 1999, and 2000 respectively. Fifty-four men sought follow-up care<sup>3</sup>.

## DISCUSSION

### Screening for Prostate Cancer

A PSA and DRE were used in the mass prostate cancer screening clinics upon which this study builds. Of the screening tests for early prostate cancer, only the PSA tumor marker blood test stands out as both convenient to administer and potentially sensitive enough to detect prostate cancer while it is localized to the prostate gland (Merrill, & Stephenson, 2000). In a recent study Labrie and colleagues (1999), compared the prostate cancer mortality rates between 1989 and 1996 of men who were screened for PSA with those who were not. They found that early diagnosis and treatment through PSA screening resulted in a dramatic decrease in deaths from prostate cancer. As many as 20% of men with normal PSA test results may be diagnosed with prostate cancer by a DRE. There is general agreement that the DRE also fails to identify a substantial proportion of men with prostate cancer. Thus, the use of both tests leads to the best detection of prostate cancer.

However, not all who are concerned with prostate cancer diagnosis and treatment support screening. The role of PSA as a screening test for prostate cancer is controversial, and professional medical organizations are divided on the issue of screening for prostate cancer. Proponents of screening emphasize that early detection can lead to discovery of organ-confined disease and the potential for cure. Opponents point to the lack of credible evidence that screening is associated with decreased mortality (McNaughton, Collins, Stafford, & Barry, 2000). Despite scientific controversy about the appropriateness of mass prostate cancer screening among population groups, the American Cancer Society (ACS 2001), National Medical Association, American College of Radiology, and American Urological Association (1992), recommend that annual DRE screening begin at age 40 for asymptomatic men; and DRE and PSA at age 50 for asymptomatic men, even without family history. They recommend that screening start at age 40 for men of African descent and for men with a family history of prostate cancer. In contrast, a lack of consensus on PSA screening is reflected in the diversity of recommendations from other medical and physician organizations. For example, in 2000, the American Medical Association voted against adopting screening guidelines on PSA at age 50. The U.S. Preventive Services Task Force (1996) only recommends PSA/DRE screening for men with life expectancies of at least 10 years. The American College of Preventive Medicine does not recommend routine screening for prostate cancer with DRE or PSA (Harris, et al 2001; Woolf, 2001).

Prostate cancer screening with the PSA is recommended by several professional organizations, and it has become standard in many medical practices. There is less consensus, however, about the level at

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<sup>3</sup> Upon follow up, it was discovered that two men died from causes apparently unrelated to prostate disease. Their wives did not indicate that they had followed up on their abnormal screening results.

which an additional course of action should be recommended once a PSA test has been done. Although a serum level between 0 ng/mL and 4.0 ng/mL PSA is considered normal, it has been suggested that the upper limit of normal (i.e., 4 ng/mL) might be too high, particularly for younger (i.e., 45-55 years of age) men where the prostate size is small, and that any results above 2.5-3.0 ng/mL might warrant a referral to a urologist (Elhilali, 2000). Other recent randomized studies also demonstrate that treatment of localized prostate cancer saves lives. With appropriate screening 92%-99% of prostate cancers can be diagnosed at the localized stage with no signs of bone metastases (Labrie, 2000). Available data show that an increase in acceptance and participation in regular PSA/DRE screening can markedly reduce mortality.

### Characteristics of screening participants

Frank-Stromborg, 2000, previously described community based screening in rural Illinois. Our findings differed slightly from Frank-Stromborg's work. Our population consisted largely of White men older than 50 (73.7%), educated, and currently or before retirement likely to work in skilled occupations. Frank-Stromborg's more rural population primarily consisted of men who were between the ages of 40 and 60 (69.8%), White (91.4%), employed in a profession (30%) or in a service occupation (20.9%), and they did not have a relative with prostate cancer (75.2%). The mean age for our population was 58.74 years. Twenty men between the ages of 25 and 39 participated: 14 of them were screened in 1998, and one was screened in 1999. Frank-Stromborg's rural Illinois population had a mean age of 58.6, which is almost identical to the mean age for our study participants. Experts have found that prostate cancer tends to occur more frequently in African men, often at a younger age than in White men, and the cancer can be a more aggressive disease. Experts can't agree, however, that the optimal age to screen African American men is 40 years versus 50 years of age (Brawley, Knopf, & Merrill, 1998; Gerard, & Frank-Stromborg, 1998).

Weinrich, (1998; 2000) and Tingen, 1997 studied prostate cancer screening participation among African American men, and found the significant demographic predictors were race, age, and income. In the Weinrich study, African American men were less likely to go for screening than White men were, and participation increased as age increased. Men with lower family incomes were less likely to be screened, and marital status (being married) positively influences screening. While marital status was not measured in this study, men often cited that the encouragement of a spouse or loved one encouraged them to get screened.

### Follow Up of Abnormal DRE and PSA test results

There is a dearth in the literature on the follow up aspect of mass prostate cancer screening. Myers et al (2001) conducted telephone interviews with 413 African American men in Philadelphia. The men were hospitalized for reasons unrelated to prostatic disease and were not being screened for prostate cancer. They were asked about their intent to follow up on abnormal findings if at some future time they were to undergo a PSA test. Eighty-six percent said that they thought they would follow-up. In contrast, in this study, the focus was on men who actually underwent screening. This study summarized each man's response about why he had not taken the results of his tests to a physician for follow up. Reasons given for not engaging in follow up included a personal decision to wait for a year to see if the number increased (*the PSA result did not sound like a high number to them*), and they did not feel 'bad' (*meaning that they did not experience symptoms that might indicate a problem*). Some men said they just never got around to talking to a physician about their results. During the study telephone interviews none of the

men cited economics (lack of health insurance, no source of care) as reasons why they did not follow-up. In Weinrich's work (2000), six barriers were found to be more significant in predicting initial participation in prostate cancer screening: Put it off, doctor hours not convenient, didn't know kind of doctor, didn't know where to go, and refuse to go. Women have been shown to worry when they have abnormal test results (Lerman, & Rimer, 1993; Lipkus, Halabi, Striago, & Rimer, 2000). However, none of the men reached by telephone cited "worry" as a reason that they did not take their abnormal results to a physician for follow-up. The number of men who chose to follow-up on abnormal test findings was dissimilar between years 1998, 1999, and 2000. Since different numbers of men who followed up had been screened in the previous year, it is unknown what other factors may have influenced their desire to follow up.

Failure to determine whether a participant had followed up on abnormal results included: wrong phone number, the phone number was disconnected; moved to another city-address unknown; the participant was never at home when contact was attempted; or another person at the household answered and seemed hesitant to give the participant a message to return a call to the study investigator, and the participant's death.

### Motivation for Screening

The findings in our study were consistent with other studies reported in the literature. For example, 'to preserve health' and concern expressed about their general health and general health maintenance has been frequently cited by African American men (Scroggins, & Bartley, 1999). Investigators have found that among women, physician recommendation is strongly related to cancer screening. This variable was not measured in this study, however, a large number of men who were screened had access to health care which was indicated by their responses to questionnaire items: *"Do you have a family doctor?"* And, *"When was the last time you went to see a doctor for anything about your health?"*

## FOCUS GROUP METHODS

Six focus groups were used as a part of this study to determine concerns, attitudes, and beliefs about prostate cancer and prostate cancer screening that may serve as barriers to seeking testing among African American men. Focus groups, a qualitative research technique, was selected as a research method for the African American men's discussions. This methodology provided insight into their attitudes, beliefs, motives, and behaviors about prostate cancer screening.

### Sample

Six focus groups were identified with participants from across the city of Durham. Initially, a maximum of 15 men who met the inclusion criteria (Appendix F) was contacted. The six groups included 15 men from a low-income housing area, 9 men from a neighborhood of low to moderate income residents who identified with community center activities sponsored by two small churches; 12 college graduated fraternity members, 7 men from the police force, and 7 sanitation workers. The investigator identified each group with a title that described their residence, employment, fraternal order, or church/community group affiliation (Table 7). A total of 58 men presented for the focus groups.

### Materials

A focus group moderator's guide was developed by the investigator based upon her experience with eliciting details in focus group discussions. The focus group script is displayed in Appendix G.

### Procedure

The research team met to plan strategies and the procedures for the six focus groups. When the research proposal was written, the investigator planned to hire the same individual who would be very familiar with the Durham community and who also possessed skills to enter data for the study. When the study team began planning participant recruitment, the investigator experienced frustration because none of the study staff was both knowledgeable about the African American community and also proficient in data entry. In the beginning, the recruitment phase was slowed while recruitment strategies were reevaluated. The investigator took on full responsibility for participant recruitment. During the planning phase for the grant, the investigator had identified church, fraternal, civic, and barbershops as places where recruitment would occur. Recruitment strategies were modified. The investigator started by making contact with work and social colleagues known to her in Durham's African American community. Those contacts made suggestions for other people who might be helpful in identifying community informants. The community informants were individuals who were well known in their communities as good citizens, "someone who knew everyone", and who was looked up to by their peers and neighbors. The study's purpose was explained to the informants, along with the inclusion criteria to be followed. Informants suggested at least 15-20 names and made a list of those potential participants along with their phone numbers. The investigator called each individual on the list and double-checked the inclusion criteria. Those who met the inclusion criteria were read the Consent for Focus Group Participation (Appendix H). The form was hand delivered to each potential participant by the Informant, signed, and witnessed; each potential participation received a copy to keep. Identical procedures were used to recruit participants for the six focus groups. Recruitment was stratified by profession, civic group, location of residence, and church size. This provided a sample of participants from a large cross-section of the Durham community.

Focus groups were conducted by a three-person team. For each of the groups, the investigator opened the sessions by introducing herself, the moderator, and the research assistant. The African American male social worker who moderated the groups and the study investigator were experienced in conducting focus groups. The individual who recorded the group discussions also worked with the study as the main research assistant. The purpose of the study was explained. All of the men who came agreed to participate in the study. They were asked to read and sign the consent forms (Appendix H and I) and given a copy to keep. Before the groups started, each participant was asked to complete a brief data form (Appendix J). This one page form had nine items of demographic data and information about use of health care including ever had a prostate examination. The forms were completed and collected, then the focus group discussions started. The investigator excused herself from the group during the discussion.

For participant introductions, each man was asked to state his name and to share something about himself. Focus group participants were referred to by first names or in some cases where older men were participating, by 'Mr' preceding the individual's last name (*men who appeared more senior and in their late 70's and 80's. It is an expected and accepted custom among African Americans that the most senior members of an audience are addressed with titles.*) The term 'focus group' was explained to the group, and a summary statement of the topic to be discussed was given. The group was told that there were no right or wrong answers, only feelings and opinions, all points of view were welcomed, and that each



person would have an equal chance to express himself. They were asked to speak one person at a time so that each person could be heard. Participants were encouraged to respond to each other and to the moderator as well. Further, they were told that to disagree politely with someone was permitted providing they admitted that they disagreed at the beginning and said why they disagreed.

Focus group discussion started with an initial question posed to the group, and each member answered briefly or elaborated (Focus Group Moderator Guide Appendix E). Questions were directed from general ones about men's health concerns, toward questions about use of health care, cancer, prostate cancer awareness and prostate cancer screening. The participants' responses guided the next questions, directing and probing them toward sharing a clear understanding of their attitudes and concerns.

Sessions lasted 1 1/2 to 2 hours each, and they were recorded using two tape recorders with flat microphones simultaneously (one for backup), with hand written notes taken by the research assistant. At the closure of the focus group discussion, participants were reassured of confidentiality and proper use of the information. A 15-minute video, *Prostate Cancer: One More River To Cross* (Displaced Videos, Inc.) was shown to the group. This video features three African American brothers discussing how they were diagnosed with prostate cancer following screening, their treatment, and return to normal, healthy lives. Afterwards, the investigator returned to the room where the focus group discussion had taken place. The participants were invited to ask any additional questions precipitated by the discussion and the videotape, and information was provided by the investigator to clarify misunderstandings about prostate cancer and prostate cancer screening.

Participants were each given \$25 at the end of each session as an incentive for their participation. They were informed of the dates of the free prostate cancer screening clinics. Refreshments were provided. Participants left to go home, or mingled and talked socially with each other at the end of the groups.

### Data Analysis

Following each of the six focus groups, response text from the focus groups and in-depth interviews were transcribed verbatim by a professional transcriptionist. Each transcript was reviewed by the moderator along with the notes taken at all of the focus group sessions. The *Atlas-ti* computer software package for text analysis was used, along with non-computerized hand coding.

### Results

Themes were identified as they emerged from each set of focus group data. Analysis of the focus groups found major themes that represented barriers to prostate screening. These themes included: lack of awareness that early detection for prostate cancer could mean earlier treatment; lack of trust to discuss personal health care issues with peers; and fatalistic view of cancer prognosis, especially for prostate cancer prognosis. Cost and access to health care did not arise as a barrier to screening. Among the groups, a few men in each group hesitantly discussed concern for the invasive nature of the DRE. There was concern about embarrassment, but greater concern for one to two men in each group that the DRE had sexual connotation that made the DRE repulsive and unacceptable.

## Discussion

Focus groups are carefully planned and conducted focused discussions among homogenous respondents (for example, similar social class, cultural experience, and similar points in the life cycle). Focus groups have been used widely to understand how African American women feel about breast and cervical cancer prevention and detection measures. However, the literature lacks a wide documentation of this approach among African American men to explore and draw out their insights for their concerns, attitudes, perceptions, and barriers to prostate cancer screening. O'Rourke (1998) used focus groups retrospectively with twelve patients already diagnosed with prostate cancer, and their spouses, to explore the decision making process about cancer treatment. Robinson (1996) used focus groups with 56 African American men to assess incentives and barriers to participating in prostate cancer research, specifically prostate cancer clinical trials. The racial disparity in prostate cancer is indicative that special methods are needed to increase earlier detection and treatment modalities among African American men.

Focus group discussions usually are conducted with approximately seven to 10 participants by a skilled moderator. Over recruitment (*inviting more than 15 participants*) was done for these groups to insure that if a potential participant was unable to attend at the last minute, there would be an adequate number of participation to accomplish the study's goals. The small group size facilitates sharing of insights, yet, is large enough to provide diversity of perception. Focus groups are usually composed of people who do not know each other. However, in small towns and cities, and as was evident in this study, the men came from similar backgrounds, employment, or group affiliation, so anonymity was virtually impossible. Group members influence and build upon the responses and ideas presented in the discussion. The combined effort of the group will produce a wider range of information and insight. Since no individual is required to answer any given question, the individual's responses can be more spontaneous (Krueger, 1994). The discussion is relaxed, comfortable, and often enjoyable for participants as they share their ideas and perceptions, nurtured by the moderator.

In this study, focus groups were used to engage the African American men to talk comfortably, and express their attitudes and concerns about prostate cancer screening and prostate cancer. The moderator observed the discussion and gained first-hand insights into the respondents' behaviors, attitudes, language, and feelings. Immediately following each group, the investigator, moderator, and research assistant met for approximately 30 minutes to discuss with the investigator emotions and feelings that could not easily be captured by listening to the audiotape recording and reading the script. The focus groups provided in-depth understanding about each individual's responses. These discussions focused attention on the perceptions and experiences of the participants. What individuals say they believe, the feelings they express, and explanations they give are treated as significant realities. They provided greater depth of response and, therefore, greater consequent understanding than quantitative techniques could have for this aspect of the study.

Concerns and attitudes about screening expressed by the focus group participants and about prevention-focused health seeking behaviors were similar to findings by Plowden (2000). Plowden's focus group participants came from educational backgrounds of high school completion and trade school. Few had attended or completed college programs. Perceived severity, susceptibility, and benefits were identified as motivators to seeking care and practicing health promotion behavior.

As diagnostic and treatment procedures become more widely used in clinical practice, attention is directed toward informing the general public about them. In the late 1980's, the Prostate Cancer Education Council, Crawford (1997) with members from disciplines across the United States, sponsored a survey of men over the age of 40 years to determine the level of awareness and concern about prostate cancer. Two-thirds of the men stated that they had not had an examination in the last year, and of those who did, only 50% had the recommended screenings. Cancer ranked near the bottom of health issues discussed, behind hypertension, colorectal cancer and melanoma. The Council concluded that prostate cancer was an ignored male disease (DeAntoni & Crawford, 1994). Myers et al (1996) concluded that psychological and social influence factors are associated with screening intention.

The videotape used in this study focus groups seemed to reinforce what they had learned from the focus group discussions. Volk, et al (1999) used a videotape to improve the core knowledge of asymptomatic men regarding prostate cancer. In that study, a control and an intervention group were used. Results showed no significant difference between the two groups before and after baseline. Myers (1996) on the other hand, found that as African American men aged to 50 years and older, were targeted with intensive education interventions in a private clinic setting (as compared to minimal interventions) they were less likely to indicate that they "intended to screen". Experts in the cancer detection field point out that those men are ones who gain knowledge that empowers them to make the best informed decision about preventive health care. Men in this study's focus groups showed a great deal of interest and appreciation for having been invited to participate.

Surprisingly, none of the 58 men who participated in the focus groups attended either of the year 2000 free prostate cancer clinics. It is not known if they used a personal physician for screening in that year. Barber et al (1998) found in a study in Michigan that mass screening was most popular among white men. African American men were twice as likely as white men to choose private appointment over mass screening.

There were advantages to using focus groups for this study. People, by nature, are social and interact with each other. Focus groups will place them in real-life, natural situations. One-to-one interactions are not able to capture the dynamic nature of such group interactions. Further focus groups discussions allowed the moderator for this study to explore any unanticipated issues not possible within a more structured questioning sequence. By its very nature, the focus group technique dealt with the emotional and contextual aspects of the men's feelings and attitudes about prostate cancer rather than with objective, measurable behavior. It added "feel" and "texture" (Yin, 1994). The small numbers of participants selected were not randomly selected in a true sense as one would do in quantitative methodology. Because of this, results from these six focus groups generalizes what we know about prostate cancer screening for African American males in Durham, North Carolina. No attempt is made to draw firm conclusions about the African American population at large. In focus groups, explanations are sought for the data, rather than data being collected to test pre-established hypotheses (Stake, 1995).

## KEY RESEARCH ACCOMPLISHMENTS

During this one-year study, two key research accomplishments were achieved:

- Developed and maintained the first database to track which men participate in free prostate cancer screening in Durham, North Carolina. This will become a longitudinal database. This was the first time that the sponsors and clinic administrators for the free screening clinics (at Duke or Lincoln) had known the sociodemographic statistics on the clinic participants. For example, prior to the first year of the study, it was assumed by the sponsors and clinic administrators that only African American men who were patients at Lincoln Community Health Center went there for the free screening.
- The investigator, a junior researcher, had the opportunity to work with a research team and engage in a mentor-mentee relationship while conducting research on an important topic in the area of cancer prevention and detection.

## REPORTABLE OUTCOMES

- Draft Manuscript developed. Query and abstract submitted to Oncology Nursing Forum Journal; letter received conveying the editorial staff's interest in reviewing the full (Appendix K).
- Five abstracts were submitted and accepted for nursing and public health meetings and conventions. The investigator gave 15-20 minute podium presentations or displayed a poster about the study at those meetings.

Author for the following five poster or podium presentations: Marva Mizell Price

Poster Presentation, "Free Community Prostate Cancer Screening: Who Attends and Why?" School of Public Health Minority Health Conference, University of North Carolina, Chapel Hill, February 16, 2001.

Podium Presentation, American Public Health Association, "Free Community Prostate Cancer Screening: Who Attends and Why?" Boston, November 15, 2000.

Podium Presentation, National Black Nurses Convention, "Follow-up of Men who Participate in a Free Community Day Prostate Cancer Screening Clinic" and "Generational Influences on Cervical Cancer Screening", Washington, DC, August 8, 2000.

Poster Presentation, 11<sup>th</sup> International Conference on Cancer Nursing, "Follow-up of Men who Participate in a Free Community Day Prostate Cancer Screening Clinic", Oslo, Norway. July 30-August 3, 2000.

Podium Presentation, National Organization of Nurse Practitioner Faculties (NONPF) 26<sup>th</sup> Annual Conference, "Creating a Faculty Research Opportunity with a Community Prostate Cancer Screening Program", Washington, D.C. April 19, 2000.

## CONCLUSIONS

### So What

This study has added to the limited scientific knowledge about attendance at free screening clinics. Nearly all of the previous study on mass screening has been conducted by nurse researcher Weinrich and her colleagues. Those works were conducted over the latter portion of the past decade. As clinicians and medical practitioners strive for consensus on prostate cancer screening, continued research contributions are needed to address mens' screening behavior, especially for prostate cancer prevention among minority men. Further research inquiry is needed to examine issues that promote sustained screening. A major concern raised by this study is the number of men (375) who did not return for screening in the subsequent year. Where did they go for screening? For those with abnormal results, how could they be adequately motivated to follow up with an appropriate health care provider? The investigator submitted a proposal that proposes further study to incorporate specific goals and strategies aimed to address these issues (Department of Defense Prostate Cancer Research Program – Health Disparity Training Prostate Scholars Award Program, proposal submission June 6, 2001).

A recommendation that might help to facilitate better follow up, would be for the free screening clinic organizers to mail a copy of the test results to participants' health care providers. Although the consent form for the free screening states that test results will be communicated to the man's physician, this important aspect of the screening was not observed to have been incorporated during the study years.

Results show that innovative and culturally sensitive strategies must be designed, especially to encourage African American men who are less well educated to seek prostate cancer screening. There is a need for information about prostate cancer and prostate cancer screening among men and their significant others and families, especially for men in lower income levels and those in less skilled and professional employment areas. In the investigator's recent proposal to the Department of Defense Prostate Cancer Research Program, Health Disparity Training, Prostate Scholars Award Program (June 2001), she proposed to test methods to promote sustained screening.

The controversy about who and at under which conditions to screen needs consensus building. However, while differences remain among cancer and policy organizations and professional groups, individual physicians can help each of their male patient's make the best informed decision about annual screening, based on their risk factors and general health. Low-cost, accessible community screening should be promoted among African American men to close the gap in morbidity and mortality from prostate cancer. More research inquiry is needed to address the health disparity that remains for prostate cancer, particularly for African American men.

## FUTURE WORK

Weinrich et al. hypothesizes that to reduce prostate mortality rates in African American men, health care providers need to make a concerted effort to increase their education about prostate cancer screening. To be effective, recruitment of African American men must include provider/health site orientation as well as consumer/community orientation. These findings indicate the importance of recruitment strategies moving to the community where a large number of African American men live and work (Weinrich, Boyd, Bradford, Mossa, Weinrich, 1998). For future work, the investigator is interested in studying how to sustain free prostate cancer screening, especially among African American men. The investigator wants to identify and test strategies that promote free screening to men who may not use health care resources like the majority of participants in this study. We need to understand health care and community leaders perceptions about prostate cancer screening, and what role they can play in working with other health care providers to spread the work about prevention and detection. We also need to know what recommendation providers make to men under their care and influence.

Investigation is needed to determine barriers that kept African American focus group participants from using the free screening clinics. African American men who participated in the focus groups in 1999 were notified of the year 2000 free clinics. A flyer was mailed to each of 58 men who participated in the focus groups, providing information on the dates for the fall 2000 screening. However, none of them showed up for either of the free screening sites. What were the barriers? Did they go to a private provider for their annual examination? Future work is needed to explore barriers to health care more fully, especially for men from minority groups.

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Table 1: Sociodemographic characteristics of all participants screened (n=792).

	n	%
Age (n=739; mean=58.74)		
<40 years	20	2.7
≥40 years	719	97.3
Race (n=765)		
African American/Black	346	45.2
White American	401	52.4
Other	18	2.4
Employment Status (n=744)		
Working	422	56.7
Not Working	322	43.3
Educational Attainment (n=762)		
≤ High school diploma	244	32.0
>High school diploma	518	68.0
Have a Family Doctor (n=761)		
Yes	522	68.6
No	239	31.4
Last Time Visited Dr. (n=768)		
Within 12 mos.	525	68.4
More than 1 yr. Ago	133	17.3
More than 2 yrs. Ago	110	14.3

Table 2: Sociodemographic characteristics of men screened in 1998 (n=485).

	n	%
Age (n=475; mean=57.99)		
<40 years	14	2.9
≥40 years	461	97.1
Race (n=463)		
African American/Black	219	47.3
White American	234	50.5
Other	10	2.2
Employment Status (n=438)		
Working	257	58.7
Not Working	181	41.3
Educational Attainment (n=462)		
≤ High school diploma	167	36.1
>High school diploma	295	63.9
Have a Family Doctor (n=461)		
Yes	319	69.2
No	142	30.8
Last Time Visited Dr. (n=472)		
Within 12 mos.	297	62.9
More than 1 yr. Ago	114	24.2
More than 2 yrs. Ago	61	12.9

Table 3: Sociodemographic characteristics of men screened in 1999 (n=419).

	n	%
Age (n=373; mean=60.4)		
<40 years	1	0.3
≥40 years	372	99.7
Race (n=405)		
African American/Black	166	41.0
White American	231	57.0
Other	8	2.0
Employment Status (n=397)		
Working	216	54.4
Not Working	181	45.6
Educational Attainment (n=399)		
≤ High school diploma	110	27.6
>High school diploma	289	72.4
Have a Family Doctor (n=403)		
Yes	285	70.7
No	239	29.3
Last Time Visited Dr. (n=406)		
Within 12 mos.	326	80.3
More than 1 yr. Ago	23	5.7
More than 2 yrs. Ago	57	14.0

Table 4: Sociodemographics of African American and White American men screened.

	African American		White American	
	n	%	n	%
Age	Mean=54.80 yrs.		62.22 yrs.	
<40 years	17	0.6	2	0.5
≥40 years	322	99.4	375	99.5
Employment Status				
Working	209	63.5	197	50.8
Not Working	120	36.5	191	49.2
Educational Attainment				
≤ High school diploma	121	35.4	115	29.3
>High school diploma	221	64.6	278	70.7
Have a Family Doctor				
Yes	209	61.8	177	74.5
No	129	38.2	101	25.5
Last Time Visited Dr.				
Within 12 mos.	230	68.0	271	68.6
More than 1 yr. Ago	66	19.5	60	15.2
More than 2 yrs. Ago	42	18.3	64	16.2

Table 5: Sociodemographic characteristics of African American and White American men screened in 1998.

	African American		White American	
	n	%	n	%
Age	Mean=54.27 yrs.		61.36 yrs.	
<40 years	11	5.1	2	0.9
≥40 years	204	94.9	229	99.1
Employment Status				
Working	136	65.7	113	51.4
Not Working	71	34.3	107	48.6
Educational Attainment				
≤ High school diploma	78	36.1	82	35.2
>High school diploma	138	63.9	151	64.8
Have a Family Doctor				
Yes	135	62.2	177	75.6
No	82	37.8	54	23.4
Last Time Visited Dr.				
Within 12 mos.	128	60.9	148	64.3
More than 1 yr. Ago	56	26.7	49	21.3
More than 2 yrs. Ago	26	12.4	33	14.3

Table 6: Sociodemographic characteristics of African American and White American men screened in 1999.

	African American		White American	
	n	%	n	%
Age	Mean=56.02 yrs.		63.57 yrs.	
<40 years	7	4.7	1	0.5
≥40 years	142	95.3	206	99.5
Employment Status				
Working	97	61.8	111	49.8
Not Working	60	38.2	112	50.2
Educational Attainment				
≤ High school diploma	56	34.6	52	23.5
>High school diploma	106	65.4	169	76.5
Have a Family Doctor				
Yes	101	63.5	170	73.6
No	58	36.5	58	25.1
Last Time Visited Dr.				
Within 12 mos.	137	84.6	176	77.2
More than 1 yr. Ago	9	5.6	13	5.7
More than 2 yrs. Ago	16	9.9	39	17.1



Table 7: Description Of Focus Groups

GROUP NAME	MEETING PLACE FOR FOCUS GROUP	GROUP DESCRIPTION	NUMBER OF PARTICIPANTS	AGE RANGE	MEAN AGE
Walltown	Multi-purpose room in the Walltown Community Center	Participants were recruited from the Walltown neighborhood, a well-established African American older low to moderate income neighborhood, whose family and community activities center around two protestant churches. The churches are renewing the community and have established a community center	9	40-68	48.11
City Workers	Meeting hall for the Sanitation Unionized Workers	Participants were recruited from employees of the City of Durham Sanitation Department	7	41-56	47.86
Eagle Summit	Eagle Summit Church in a Sunday School classroom. The church, founded in the mid-1990's, is located in a shopping center in the former site of an abandoned discount variety store that was remodeled into a church	Participants were recruited among members of a moderate size Pentacostal congregation (approximately 300 member congregation)	8	43-54	48.36
Morreene Road	Community Room of low-income housing units for older adults	Participants were recruited from residents of the Morreene Road Housing Project	15	41-78	54.20
Police Department	Durham Police Department meeting room	Participants were recruited from members of the Durham Police Department	7	33-64 <sup>4</sup>	46.43
Omega Psi Phi Fraternity	Durham Chapter in the fraternity house meeting room	Participants were recruited from the active alumni membership of this African American fraternity. Participants were college and professional school graduates.	12	40-61	48.42

<sup>4</sup> The 33 year old participant had indicated his age as 40 during the review of the Inclusion Criteria; he listed his date of birth to correspond with 33 years of age on the Focus Group Data form.

Table 8: Characteristics of Focus Group Participants (n=58).

	n	%
Age (mean=49.55; s.d.=7.98)		
<40 years	1	1.7
≥40 years	57	98.3
Educational Attainment		
≤ High school diploma	14	24.1
>High school diploma	44	75.9
Have a Family Doctor		
Yes	43	74.1
No	15	25.9
Ever Had a Prostate Exam		
Yes	40	69.0
No	18	31.0

## APPENDICES

Form \_\_\_\_\_ Patient \_\_\_\_\_

PROSTATE CANCER SCREENING  
CONSENT FORM

Duke University Health System  
Surgical Oncology Clinic, Duke South  
October 3, 1998

Welcome to the Prostate Cancer Awareness Week Screening Program. Today, we will use a digital rectal exam and a blood test (Prostatic Specific Antigen, PSA) to screen you for prostate cancer. The digital rectal examination is performed by the physician inserting a gloved index finger into the rectum and gently pressing against the prostate. If any lumps, bumps, or irregularities are felt, you will be referred to your doctor for further evaluation. Although some tumors may be detected by this exam, no test is completely accurate in the detection of prostate cancer. Furthermore, an abnormal exam does not necessarily imply the presence of cancer.

The National Cancer Institute and the Prostate Cancer Education Council recommend an annual prostate cancer exam for all men over the age of 40. While we know that the only way to cure prostate cancer is to detect it early before it has spread to other areas of the body, there is not yet absolute proof that screening will prolong the lives of men who do not yet have symptoms of prostate cancer.

In order to be screened, all participants must read and sign this *Consent Form* and fill out the attached questionnaire. This screening is performed free of charge.

The digital rectal exam may initially be uncomfortable. This discomfort should resolve with time. The minimal potential of risks associated with digital rectal exams include rectal bleeding and irritation of anatomical irregularities.

You will be provided with a copy of your examination results. If your examination is marked *normal*, we suggest that you share it with your personal physician and schedule future annual prostate exams. If your examination is marked *abnormal* (*suspicious, likely, or certain*) we recommend that you contact your personal physician as soon as possible for further evaluation. If you do not have a personal physician, we have a urology referral list for you.

Consent

By voluntarily participating in the Prostate Cancer Screening Program, I recognize and accept all risks associated with it. I understand that the program will only screen for abnormalities in the prostate area and does not constitute a complete medical exam or diagnosis. For a diagnosis of a medical problem, I must see a physician for a complete medical exam.

I hereby release The Prostate Cancer Education Council, National Cancer Institute, National Cancer Care Foundation, American Urological Association, American Foundation for Urologic Disease, Association of Community Cancer Care Centers, Duke University Medical Center, Private Diagnostic Clinic, and any other organization involved in this program, and their agents, partners, and/or employees from all liabilities, medical claims or expenses which may arise from my participation or from any injury sustained during this event.

I, \_\_\_\_\_, have read this form and understand its contents. I understand that the results will be released to me and the confidentiality of the data will be maintained within legal limits and that information will be forwarded to the Prostate Cancer Education Council and my personal physician. This information may be used in the future for statistical evaluation and scientific literature. However, I will not be individually identified in any recognizable way. I also allow Duke University Medical Center to contact me at a later date regarding this examination.

\_\_\_\_\_  
Participant Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness Signature

\_\_\_\_\_  
Date

**Prostate Cancer Screening Questionnaire 1999<sup>©</sup>**

(This information will be kept confidential and used only for future prostate cancer education and research.)

**Section I** (To be completed by participant)

First Name	Last Name	M.I.	Date of Birth
Street Address		Apt.	
City		State	Zip Code
Phone	Social Security Number		Your Social Security Number will only be used to find records from previous or future years, and will not be given to any agency or individual.

- 1 Race:** White .....1  
Black/African-American .....**2**  
Latino/Hispanic .....3  
Oriental/Asian .....4  
Other (Specify) .....5

**2 Height:** \_\_\_\_\_ Feet \_\_\_\_\_ Inches  
**Weight:** \_\_\_\_\_ Lbs.

- 3 Marital Status** (Circle the number below)  
Married .....1 Divorced .....3  
Single .....2 Widowed .....4

- 4 How many rectal exams of the prostate have you had in the past 3 years?**  
none .....0 2 .....2  
1 .....1 **3 or more** .....3  
**How many PSA tests have you had in the past three years?**  
none .....0 4-6 .....2  
**1-3** .....1 7 or more .....3

**5 Diet and Exercise** (Circle one)

Overall, thinking about the foods you eat, how would you rank your diet in fat?

High .....1 Medium **2** Low .....3

Did you take vitamin E supplements most days in the past month?

Yes **1** No .....2

During the past month, did you participate in any physical activities such as running, calisthenics, golf, gardening, or walking?

Yes **1** No .....2

**6 Why are you being tested for prostate cancer?**  
(Check most important reason)

I am very health conscious .....1

I have a family history of prostate cancer .....**2**

I am at very high risk .....3

My wife insisted .....4

My children insisted .....5

I want to be certain I don't have it .....6

**Medical History****7 Did you receive an exam during a previous Prostate Cancer Awareness Week?** (Check all years that apply)

1991 ..... <input type="checkbox"/>	1995 ..... <input type="checkbox"/>
1992 ..... <input type="checkbox"/>	1996 ..... <input checked="" type="checkbox"/>
1993 ..... <input type="checkbox"/>	1997 ..... <input checked="" type="checkbox"/>
1994 ..... <input type="checkbox"/>	1998 ..... <input checked="" type="checkbox"/>

**8 If you participated in Prostate Cancer Awareness Week previously and were told you had an ABNORMAL exam (DRE or PSA), did you have a subsequent check-up and/or biopsy?** (Circle number)

Yes .....1 No .....**2**

**If not, why not?** (Circle number)

Did not think it was important .....1

Was afraid to find out if I had cancer .....2

Was too expensive for me .....3

Did not understand I was supposed to do that .....4

Don't know .....5

**9 Would you be willing to participate in prostate cancer research studies?**

Yes **1** No .....**2**

**Would you be willing to participate in research on genetic testing for prostate cancer?**

Yes **1** No .....**2**

**10 Have you ever had any of the following?**

(Circle number for each item listed below)

	Yes Have Had	No Have Not Had	Don't Know
--	-----------------	--------------------	---------------

Diabetes .....1 .....**2** .....3

Heart Attack .....1 .....**2** .....3

Heart Disease .....1 .....**2** .....3

Prostate Infection (Prostatitis) .....1 .....**2** .....3

Enlarged Prostate (BPH) .....1 .....**2** .....3

If yes, are you currently on medication ☐ Yes ☐ No

If yes, Proscar .....1 Cardura, Hytrin, or Flomax .....2

Prostate Surgery .....1 .....2 .....3

Prostate Cancer .....1 .....2 .....3

Vasectomy .....1 .....2 .....3

**If Had a Vasectomy, Year Performed** \_\_\_\_\_

**Family History of Cancer**

Father's Father had Prostate Cancer .....1 .....2 .....3

Father's Brother(s) had Prostate Cancer .....1 .....2 .....3

Father had Prostate Cancer .....**1** .....2 .....3

Brother had Prostate Cancer .....1 .....2 .....3

Mother's family had Prostate Cancer .....1 .....2 .....3

Mother's family had Breast Cancer .....1 .....2 .....3

Mother had Breast Cancer .....1 .....2 .....3

**Urinary Symptoms Evaluation**

Over the past month, have you had any of the following problems with your urination?

	Not at all	Less than 1 time in 5	Less than half the time	Half the time	More than half the time	Almost always	
How often have you had a sensation of not emptying your bladder completely after you finish urinating? .....	0	1	2	3	4	5	
How often have you had to urinate again less than two hours after you finish urinating? .....	0	1	2	3	4	5	
How often have you found that you stopped and started again several times when you urinate? .....	0	1	2	3	4	5	
How often have you found it difficult to postpone urination? .....	0	1	2	3	4	5	
How often have you had a weak urinary stream? .....	0	1	2	3	4	5	
How often do you push or strain to begin urination? .....	0	1	2	3	4	5	
	Never	Once	Twice	Three times	Four times	Five or more times	
How many times do you typically get up to urinate from the time you go to bed until the time you get up in the morning? .....	0	1	2	3	4	5	
	Delighted	Pleased	Mostly satisfied	Mixed about	Mostly dissatisfied	Unhappy	Terrible
If you were to spend the rest of your life with your urinary condition just the way it is now, how would you feel? .....	0	1	2	3	4	5	6

**Digital Rectal Exam Results 1999****Section II (To be completed by Physician)****1 Digital Rectal Exam Results**

- Normal ..... 1 (Skip to Section III)  
Enlarged - BPH ..... 2 (Complete Section II, Box 2.A.)  
Abnormal - Not Suspicious ..... 3 (Skip to Section III)  
Abnormal - Suspicious ..... 4 (Complete Section II, Box 2.B-D)  
Patient Refused ..... 5 (Skip to Section III)

**2 A. BPH (Circle one number below.)**

1+ (15-20g)      2+ (20-30g)      3+ (30-40g)      4+ (>40g)

**B. Abnormal (suspicious for cancer)**

- Asymmetrical ..... 1  
Induration ..... 2  
Nodularity ..... 3

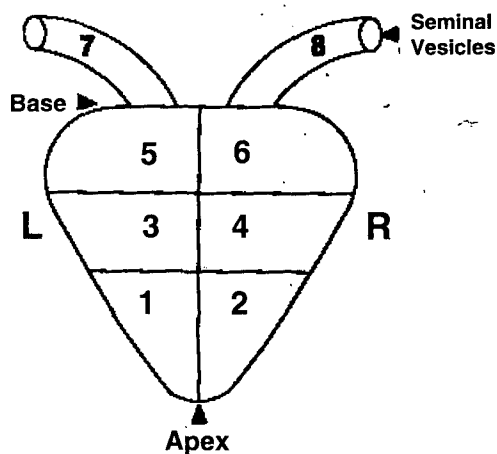
**C. Grade of induration**

- Firm (consistency of tennis ball) ..... 1  
Firmer (consistency of softball) ..... 2  
Hard (Consistency of marble) ..... 3

**D. Clinical Staging**

- T<sub>2</sub> ..... 1  
T<sub>3</sub> ..... 2

Please indicate location of nodule(s):



Examining Physician's Name

Signature

Date

**Section III Participant Information****RECOMMENDATIONS (Circle one):**

- No Action Necessary ..... 1  
See a Urologist ..... 2  
Abnormal-suspicious DRE ..... Yes No  
Urinary Symptoms ..... Yes No  
Other .....

**Digital rectal exam results (Circle one):**

- Normal Exam ..... 1 No action necessary. Recommend an annual exam unless the PSA level (blood test) is elevated.  
Abnormal-Suspicious Exam ..... 2 See your urologist for further prostate evaluation regardless of the PSA level (blood test) results. However, wait to schedule an appointment until you receive your blood tests results. The results of your blood test will help your physician to determine further evaluation.  
BPH ..... 3 This is an enlargement of the prostate and only needs treatment when you have problem voiding. You will need further evaluation if the PSA level (blood test) is elevated.

*Thank you for participating. Please return next year.*

**RIGHT**

**WRONG**

0	1	2	3	4	5	6	7	8	9
10	11	12	13	14	15	16	17	18	19
20	21	22	23	24	25	26	27	28	29
30	31	32	33	34	35	36	37	38	39
40	41	42	43	44	45	46	47	48	49
50	51	52	53	54	55	56	57	58	59
60	61	62	63	64	65	66	67	68	69
70	71	72	73	74	75	76	77	78	79
80	81	82	83	84	85	86	87	88	89
90	91	92	93	94	95	96	97	98	99

**Last Name**

City

**Zip**

Home Phone# (      )
----------------------

Month Day Year

Work Phone# ( )

**6. What is your race?**

- ☐ Black or African American  
☐ White  
☐ Hispanic or Latino  
☐ Asian  
☐ American Indian  
☐ Other (please specify)

**7. Do you have a family doctor?**

- ☐ Yes  
☐ No

**8. When was the last time you went to see a doctor for anything about your health?**

- ☐ (A) This year  
☐ (B) Last year  
☐ (C) Longer than a year ago  
☐ (D) Probably more than 2 years ago

**9. Have you ever had somebody kin to you or a friend with prostate cancer?**

- (A) No  
(B) Yes

**10. You will get a letter about your test results. Is it all right to contact you by telephone sometime in months ahead if your prostate exam or blood test concerns the doctor?**

- ☐ A No  
☐ B Yes

# Appendix D: Database Code Book

## List of variables on the working file

Name		Position
PARTICIP	Year Participated Measurement Level: Scale Column Width: 8 Alignment: Right Print Format: F8 Write Format: F8	1
	Value      Label	
	1      1998 (Year 1)	
	2      1999 (Year 2)	
	3      Both	
ID	Year 1: Questionnaire id=yy0### Measurement Level: Scale Column Width: 8 Alignment: Right Print Format: F8 Write Format: F8	2
CLINIC	Year 1: Clinic Screened at Measurement Level: Nominal Column Width: 4 Alignment: Right Print Format: F6 Write Format: F6 Missing Values: 99	3
	Value      Label	
	1      Duke	
	2      Lincoln	
QUESTID2	Year 2: Questionnaire ID Measurement Level: Scale Column Width: 8 Alignment: Right Print Format: F8 Write Format: F8	4
CLINCID2	Year 2: ID given by clinic Measurement Level: Scale Column Width: 8 Alignment: Right Print Format: F8 Write Format: F8	5
FIRSTNAM	First Name Measurement Level: Nominal Column Width: 15 Alignment: Left Print Format: A15 Write Format: A15	6



LASTNAME	Last Name	8
	Measurement Level: Nominal	
	Column Width: 12 Alignment: Left	
	Print Format: A12	
	Write Format: A12	
ADDRESS1	Address	10
	Measurement Level: Nominal	
	Column Width: 20 Alignment: Left	
	Print Format: A20	
	Write Format: A20	
CITY	City	13
	Measurement Level: Nominal	
	Column Width: 15 Alignment: Left	
	Print Format: A15	
	Write Format: A15	
PHONE	Phone	15
	Measurement Level: Nominal	
	Column Width: 12 Alignment: Left	
	Print Format: A14	
	Write Format: A14	
ZIP2	Year 2: Zip code	17
	Measurement Level: Scale	
	Column Width: 8 Alignment: Right	
	Print Format: F7	
	Write Format: F7	
HOME#2		18
	Measurement Level: Scale	
	Column Width: 10 Alignment: Right	
	Print Format: F10	
	Write Format: F10	
WORK#2		19
	Measurement Level: Scale	
	Column Width: 11 Alignment: Right	
	Print Format: F10	
	Write Format: F10	
DOB	Date of Birth	20
	Measurement Level: Scale	
	Column Width: 11 Alignment: Right	
	Print Format: DATE11	
	Write Format: DATE11	

AGEYR      Year 1: Age in years      21  
Measurement Level: Scale  
Column Width: 8    Alignment: Right  
Print Format: F6.2  
Write Format: F6.2  
Missing Values: 999.00

AGECAT      Age Categories      22  
Measurement Level: Nominal  
Column Width: 8    Alignment: Right  
Print Format: F8.2  
Write Format: F8.2  
Missing Values: 99.00

Value	Label
1.00	29 or less
2.00	30-39
3.00	40-49
4.00	50-59
5.00	60+

RACE      Race      23  
Measurement Level: Nominal  
Column Width: 8    Alignment: Right  
Print Format: F4  
Write Format: F4  
Missing Values: 99

Value	Label
1	African American
2	Black/not US born
3	Latino
4	Asian
5	White
6	Am. Indian
7	Other

TYPEWORK Dictionary of Occupational Titles 24  
Measurement Level: Nominal  
Column Width: 8 Alignment: Right  
Print Format: F4.2  
Write Format: F4.2

Value	Label
1.00	Professional, Technical, Managerial
2.00	Clerical/Sales
3.00	Service
4.00	Agricultural
5.00	Processing
6.00	Machine Trades
7.00	Benchwork
8.00	Structural Work
9.00	Miscellaneous

TYPEWRK2 Year 2: Job Type 25  
Measurement Level: Nominal  
Column Width: 8 Alignment: Center  
Print Format: F8.2  
Write Format: F8.2

Value	Label
1.00	Professional/Tecnical/Managerial
2.00	Clerical/Sales
3.00	Service Occupations
4.00	Agricultural
5.00	Processing
6.00	Machine Trades
7.00	Benchwork
8.00	Structural Work
9.00	Miscellaneous

WORKSTAT Work Status 26  
 Measurement Level: Nominal  
 Column Width: 8 Alignment: Right  
 Print Format: F4  
 Write Format: F4

Value	Label
1	Retired
2	Disabled
3	Unemployed
4	Still Working

WRKSTAT2 Year 2: Are you currently 27  
 Measurement Level: Scale  
 Column Width: 8 Alignment: Center  
 Print Format: F8  
 Write Format: F8

Value	Label
1	retired
2	disabled
3	unemployed
4	still working

EDLEVEL Highest Education Level Attained 28  
 Measurement Level: Scale  
 Column Width: 8 Alignment: Right  
 Print Format: F8.2  
 Write Format: F8.2  
 Missing Values: 99.00

Value	Label
1.00	Some schooling
2.00	High School Grad
3.00	Some Tech School
4.00	Tech School Grad
5.00	Some 4 year College
6.00	4 yr college grad
7.00	some grad school
8.00	Finished Grad or Prof School

KINPCA	Have kin/friend w/PCA	29
	Measurement Level: Scale	
	Column Width: 8 Alignment: Right	
	Print Format: F8.2	
	Write Format: F8.2	
	Value      Label	
	.00      no	
	1.00     yes	
FAMDOC	Have family Dr.	30
	Measurement Level: Scale	
	Column Width: 8 Alignment: Right	
	Print Format: F8.2	
	Write Format: F8.2	
	Value      Label	
	.00      no	
	1.00     yes	
LASTTIME	Last time visited Dr. for health	31
	Measurement Level: Nominal	
	Column Width: 8 Alignment: Right	
	Print Format: F4	
	Write Format: F4	
	Value      Label	
	1      this year	
	2      more than 1 year ago	
	3      probably more than 2 years ago	
NOTIFY	Notify How?	32
	Measurement Level: Nominal	
	Column Width: 8 Alignment: Right	
	Print Format: F4	
	Write Format: F4	
	Value      Label	
	1      Letter	
	2      Phone	
	3      Return to Clinic or Docs office	

OKCONTAC Contact by phone 33  
Measurement Level: Nominal  
Column Width: 8 Alignment: Right  
Print Format: F4  
Write Format: F4

Value	Label
-------	-------

0	no
1	yes

PSA PSA value 34  
Measurement Level: Scale  
Column Width: 8 Alignment: Right  
Print Format: F5.2  
Write Format: F5.2

EXAM DRE results 35  
Measurement Level: Nominal  
Column Width: 8 Alignment: Right  
Print Format: F5  
Write Format: F5

Value	Label
-------	-------

1	Normal
2	Enlarged-BPH
3	Abnormal-Not suspicious
4	Abnormal-Suspicious

BPH BPH 36  
Measurement Level: Nominal  
Column Width: 8 Alignment: Right  
Print Format: F4  
Write Format: F4

Value	Label
-------	-------

1	15-20g
2	20-30g
3	30-40g
4	>40g

. ABNORMAL Abnormal (suspicious for cancer) 37  
 Measurement Level: Nominal  
 Column Width: 8 Alignment: Right  
 Print Format: F4  
 Write Format: F4  
  
 Value Label  
 1 Asymmetrical  
 2 Induration  
 3 Nodularity

FOLLOWUP Did person follow up with Dr. 38  
 Measurement Level: Nominal  
 Column Width: 8 Alignment: Right  
 Print Format: F4  
 Write Format: F4  
  
 Value Label  
 0 yes  
 1 don't know  
 2 no

AGEYR2 Year 2: Age in years 39  
 Measurement Level: Scale  
 Column Width: 8 Alignment: Center  
 Print Format: F8.2  
 Write Format: F8.2  
 Missing Values: 99.00

AGECAT2 Year 2: age categories 40  
 Measurement Level: Scale  
 Column Width: 8 Alignment: Center  
 Print Format: F8.2  
 Write Format: F8.2  
 Missing Values: 99.00  
  
 Value Label  
 .00 missing  
 1.00 <=39  
 2.00 >=40

CONTACT2 Year 2: Is it ok to contact you by phone? 41  
Measurement Level: Nominal  
Column Width: 6 Alignment: Center  
Print Format: F8.2  
Write Format: F8.2

Value	Label
-------	-------

.00	no
1.00	yes

LAB#2 Year 2: Lab # 42  
Measurement Level: Scale  
Column Width: 8 Alignment: Right  
Print Format: F8.2  
Write Format: F8.2

EXAM2 Year 2: DRE Results 43  
Measurement Level: Ordinal  
Column Width: 8 Alignment: Right  
Print Format: F8.2  
Write Format: F8.2

Value	Label
-------	-------

1.00	Normal
2.00	Enlarged-BPH
3.00	Abnormal-Not Suspicious
4.00	Abnormal-Suspicious

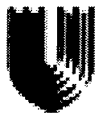
BPH2 Year 2: BPH 44  
Measurement Level: Scale  
Column Width: 8 Alignment: Right  
Print Format: F8.2  
Write Format: F8.2

Value	Label
-------	-------

1.00	15-20g
2.00	20-30g
3.00	30-40g
4.00	>40g



• ABNORML2	Year 2: Abnormal (suspicious for cancer)	45
	Measurement Level: Scale	
	Column Width: 8 Alignment: Right	
	Print Format: F8.2	
	Write Format: F8.2	
	Value      Label	
	1.00      Asymmetrical	
	2.00      Induration	
	3.00      Nodularity	
	123.00    All three	
PSA#2	Year 2: PSA#	46
	Measurement Level: Scale	
	Column Width: 8 Alignment: Right	
	Print Format: F9.1	
	Write Format: F9.1	
PSACAT2	Year 2: PSA Categorized	47
	Measurement Level: Scale	
	Column Width: 8 Alignment: Center	
	Print Format: F8.2	
	Write Format: F8.2	
	Value      Label	
	.00      psa =<4.0	
	1.00      psa=>4.1	
WHY22	Measurement Level: Nominal	48
	Column Width: 3 Alignment: Left	
	Print Format: A5	
	Write Format: A5	
WHY2	Measurement Level: Ordinal	49
	Column Width: 8 Alignment: Right	
	Print Format: F8	
	Write Format: F8	



# DUKE UNIVERSITY SCHOOL OF NURSING

FAX: 919-681-8899

## FACSIMILE TRANSMITTAL SHEET

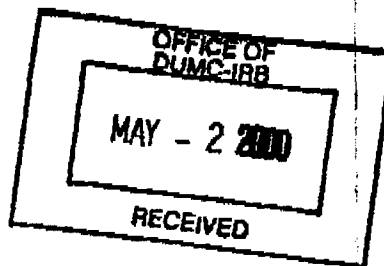
TO:	Ms. Louise Pascall	FROM:	Marva Mizell Price, DrPH, MPH, RN, FNP
COMPANY:	Protocol #PC991054, HSP Log No. A-9284	DATE:	05/12/00
FAX NUMBER:	<del>560-7744</del> 301-619-7803	TOTAL NO. OF PAGES INCLUDING COVER:	12
PHONE NUMBER:		PHONE NUMBER:	919-684-3786 x245

RE:  
Final IRB Approval at Duke Univ.

☒ URGENT ☒ FOR REVIEW ☒ PLEASE COMMENT ☐ PLEASE REPLY ☒ THANK YOU SO MUCH

Ms. Pascall:  
The final approval came from the Duke Univ. Med. Center IRB this week. I am attaching the forms. Essentially, no changes were made in the content but changes in the headers and font size. You may reply to me via email: [marva.price@duke.edu](mailto:marva.price@duke.edu)

Appendices E, F, G, H, I



## Memorandum

**To:** Dr. Falletta and the IRB  
through Emily Jackson  
**From:** Dr. Marva M. Price  
**Date:** 05/01/00  
**Re:** Protocol #1243-99-7ER Approved 7/9/99  
Editorial Corrections

***Protocol title "Using a Tracking system to Improve Prostate Cancer Screening and follow-up in a small Urban Community"***

I have made the changes per Dr. Falletta's note of April 24, 2000. Please note that the total number of pages increased to four due to adding the protocol title at the top of page 2.

Thank you.

*Approved 5/2/00*  
*[Signature]*  
JOHN M. FALLETTA, M.D.  
CHAIRMAN  
INSTITUTIONAL REVIEW BOARD

Appendices E, F, G, H, I

**FACSIMILE TRANSMISSION  
DUKE UNIVERSITY  
INSTITUTIONAL REVIEW BOARD**

TO: Dr Price  
FAX #: 681 8899  
FROM: Emily Jackson  
DATE: 5/5/00  
SUBJECT: IRB Registry # 1243-99-7ER (Approval)

If you have further questions, do not hesitate to call me at 668-0405

Thanks,

Emily Jackson

Pages (including cover sheet):

2

Institutional Review Board  
Box 2991 DUMC  
Durham, NC 27710  
Phone: 919-668-0405  
Fax: 919-668-5125

**DUKE UNIVERSITY MEDICAL CENTER  
SCHOOL OF NURSING**

(Verbal)

**Consent For Research**

**VERBAL CONSENT FOR TELEPHONE INTERVIEW**

**Using a Tracking System to Improve Prostate Cancer Screening and  
Follow-up in a Small Urban Community IRB# Protocol #1243-99-7ER**

***Telephone Script:***

Mr. \_\_\_\_\_:

I am Dr. Marva Price. I on the faculty at the Duke University School of Nursing. I am calling you because you were one of the men who participated in the Duke Medical Center free Prostate Screening Clinic last fall. You are one of approximately 124 men who are being asked to participate in this follow up study. I want to talk with you about that visit during this telephone conversation, if that is all right with you, and if you have the time to speak with me now.

Are you able to speak with me now?

[If his response is YES, continue with.....]

Mr. \_\_\_\_\_

You are being asked to voluntarily be part of a follow up study that is looking at what you decided to do about the results of your prostate screening results last fall. You may opt not to talk with me about your screening results, and if you do not wish to talk with me, it will in no way cause a problem for you in getting care from Duke in the future.

[Wait for his verbal consent to continue the interview.....]

[If he replies "NO".....thank him for his time and end the call.]

Did you receive the letter with the results?

[If he says, "NO".....tell him that I will be glad to see that he gets a copy of the letter mailed to him again, and he should expect to receive the letter in the next week ....and that I will give him another call in several weeks.]

[It is not expected that any discussion in the group should cause risk or discomfort, however, should any unforeseeable risks and discomforts arise, counseling will be available for the individual. ]

*Participation: Participation in this study is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue your participation at any time without penalty or loss of benefits.*

*All records for this study will be stored in locked files in the office of Dr. Price at Duke University School of Nursing, and access will only be permitted by Dr. Price and the study personnel.*

*It should be noted that representatives of the U.S. Army Medical Research and Materiel Command are eligible to review research records as a part of their responsibility to protect human subjects in research.*

Were you able to give your results letter to your physician?

[If he says "YES"....ask .....]

Appendix E: Consent For Research Consent For Verbal Telephone Interview

Did your physician feel any further testing is needed?

[If he says "NO"...ask .....]

What are your feelings about what you want to do with those results?

Do you have any questions about your results or about my telephone call?

There are no precautions that are expected from talking with me. However, should you have concerns, please contact me.

Thank you, Mr. \_\_\_\_\_ for talking with me.

☐ Verbal consent *was* granted for the Telephone Interview

☐ Verbal consent *was not* granted for the Telephone Interview

Appendix F Consent For Research

Consent For Focus Group Participation

DUKE UNIVERSITY MEDICAL CENTER  
SCHOOL OF NURSING

Inclusion Criteria

**Consent For Research**

**CONSENT FOR FOCUS GROUP PARTICIPATION**

**Using a Tracking System to Improve Prostate Cancer  
Screening and Follow-up in a Small Urban Community**

**IRB# Protocol #1243-99-7ER**

**Inclusion Criteria Check List**

Page 1

**Name** \_\_\_\_\_

You are being asked to voluntarily be part of a research study in the School of Nursing, Duke University Medical Center. You are being asked to participate in focus group discussion about African American men's concerns about their health.

This discussion group is a study about how men make decisions to seek and follow up on health care issues. This study is funded by a grant to the Duke University School of Nursing, Durham, North Carolina, from the United States Army Medical Research and Materiel Command.

Dr. Price of Duke University School of Nursing would like to include you as one of the men in the discussion group called a "focus group". She would like to get your thoughts on health care in general as well as health care for African American men 40 years of age and older. A man will conduct the discussion group. Dr. Price hopes to learn how to help other men figure out ways to get better health care for prevention of male health problems, especially problems of the prostate gland.

There are no known risks to being in this group discussion. Although there are no direct health benefits to you, there is the possibility that men here can help each other take steps toward more positive health care. Also, information gained from the study will be shared with health care providers in the Durham area because in the future what we learn may help health care providers in your community know how to better meet men's needs for early prostate cancer detection.

Initials of Participant \_\_\_\_\_

Initials of Witness \_\_\_\_\_

# Appendix F: Consent For Research

## Consent For Focus Group Participation Inclusion Criteria

DUKE UNIVERSITY MEDICAL CENTER  
SCHOOL OF NURSING

### Consent For Research

### CONSENT FOR FOCUS GROUP PARTICIPATION

Page 2

#### Inclusion Criteria Check List\*

<input type="checkbox"/> yes <input type="checkbox"/> no	African American or Black African American or Black <i>(of African descent but not American born, for example, men from Africa or the Caribbean)</i>
<input type="checkbox"/> yes <input type="checkbox"/> no	Male gender
<input type="checkbox"/> yes <input type="checkbox"/> no	Age $\geq 40$
<input type="checkbox"/> yes <input type="checkbox"/> no	Prostate DRE or PSA >12 months ago
<input type="checkbox"/> yes <input type="checkbox"/> no	Resident of Durham County
<input type="checkbox"/> yes <input type="checkbox"/> no	Can participate in a group scheduled in the evening
<input type="checkbox"/> yes <input type="checkbox"/> no	Will consent to be audiotaped and having notes made of group discussion
<input type="checkbox"/> yes <input type="checkbox"/> no	Understands and speaks English proficiently as measured by interchange with group recruiter
<i>(one category is required)</i>	Group Membership: <i>(must represent one of the following)</i>
<input type="checkbox"/> yes	-Church Group
<input type="checkbox"/> yes	Large church
<input type="checkbox"/> yes	Small church
<input type="checkbox"/> yes	-Fraternal Order Group
<input type="checkbox"/> yes	-Civic Group
<input type="checkbox"/> yes	-Barber Shop Customer

\*All responses must be 'yes' for inclusion in the focus groups

Participant's Permanent Address:

---



---



---

Phone Number: \_\_\_\_\_



**Using a Tracking System to Improve Prostate Cancer Screening and Follow-up in a Small Urban Community**

*Start the group at 7 pm*

6:30 – 6:45	Welcome to Focus Group and Introductions Consent forms signed	Dr. Marva Price
6:50 – 7:00	Convene Focus Group  <input type="checkbox"/> Opening Comments <b>WARM UP</b> I'd like to go around the table now and have each of you tell us your first name and a little about yourself ( <i>quickly</i> ).	Al Richmond, S.W.
7:00 – 7:25	Part 1 – Knowledge	
7:25 – 7:50	Part 2 - Cultural Factors	
7:50 - 8:15	Part 3 – Strategies	
8:15 – 8:30	Video Refreshments Incentive Payment (\$25) to participants	

**Part I. Knowledge, concerns, attitudes and beliefs about prostate cancer and screening (*heading is for your purpose..do not state it aloud*)**

1. What are the health issues facing African-American men today?

**BACKGROUND ON HEALTH**

*(General and quick - go around room)* What are health problems that concern many Black men (*or African American men*) in your age group?

What kinds of things do Black men do to take care of their health?

Are there any tests that you need to make sure you are healthy?

What are the male health problems that concern Black men in your community?

Where do men go for treatment of these male health problems?

**Probing.... on types of health care agency such as doctor's office, hospital, etc.**

When you need advice or information about your health, what do you do?

## Appendix G: Focus Group Moderator Guide

***Probing.... what do they do first, do they seek health care provider first, figure it out for themselves, or seek advice of others in family?***

Where do you get information about male health issues that you trust?

**Probing for whose advice do you trust most? What advice do you listen to most?**

LET'S LOOK AT YOUR FRIENDS OR FAMILY AS A SOURCE OF HEALTH ADVICE.

Do you and your closest male relatives discuss the male kinds of things about your health or their health?

***Probing for.... who initiates the discussion (friend, son, father, uncle, etc.).***

Does it matter whether the person you talk to is your father, or son, brother, or another man who is kin, or not kin?

***Probing for who you turn to most often now or in the past when you are concerned about male health problems?***

***What is it about that person that you are willing to seek their advice?***

What are situations in which you are more likely to talk to this person (or persons) rather than to your doctor or health care provider?

2. A number of concerns have been mentioned. Think about African-American men and prostate cancer. Is this a concern to you as an African-American?
3. What tests or screenings are used to determine if a person may have prostate cancer?
4. How important is it to be screened for prostate cancer?
5. At what age should you be screened for prostate cancer?

### **CANCER**

Some of you mentioned cancer as a health concern. (Or: No one mentioned cancer as a health concern --is cancer something you think about?)

What comes to your mind when you hear the word *cancer*?

Is there anything people can do to improve their chances of surviving cancers of the male organs?

### **PROSTATE CANCER**

**Let's talk for a moment about prostate cancer screening/or testing.** What is the purpose of the tests (if this has not come out already in the discussions)?

Can you trust prostate screening? ***Probing on perceived accuracy.***

Which health care providers usually perform the tests?

***-Probing for preference and ideas about specialists versus other health care providers such as family doctors versus urologists or men's specialists***

How often should men get tested?

***Probing....should there be a difference in how often for younger vs. older men?***

Now, what do you think are the **most important** reasons that would keep men from having the test?

Are there reasons that a man may have had a prostate test but does not go back again for another one in the future? ***-More probing for barriers such as fear, discomfort, fear of finding cancer, don't look for trouble, don't understand the results, etc.***

If you were in charge of encouraging men like yourself (or even your fathers or uncles) to get tested, what message would you tell them (***a few simple words***)?

***-Probing... What message would you say differently to the older relatives.***

Has there been any particular experience that has **helped or encouraged/discouraged** you or where you have **encourage/discouraged** someone else to get tested?

***Probing to see if they have been involved in an older male relative's decision about testing***

### **Part II. Cultural Factors That May Affect Their Interest In Seeking Prostate Cancer Screening and follow-up of Abnormal Results**

1. What have you heard about African-American men being screened for prostate cancer?
2. What have you heard about African-American men and prostate cancer?
3. What concerns do you have about being screened for prostate cancer?

## Appendix G: Focus Group Moderator Guide

4. When you hear that a man has been diagnosed with prostate cancer what do you think?

### **Part III. Factors That Can Lead To Strategies to Increase Actions Taken By African-American Men for Regular Annual Screening.**

1. Thinking back over the past 2 years what information has been shared with you about prostate cancer?
2. Has the information that you received influenced your decision regarding screening and prostate cancer?
3. How would you get information out about prostate cancer?
4. What would make you men get screened for prostate cancer?

If you were in charge of encouraging men like **yourself (or even your fathers, sons, or uncles, or other men)** to get pap smears, what message would you tell them **(a few simple words)**?

5. Of all the things that you identified that would make you men get screened which one is the important?

DUKE UNIVERSITY MEDICAL CENTER  
SCHOOL OF NURSING

**Consent For Research**

**CONSENT FOR FOCUS GROUP PARTICIPATION**

**Using a Tracking System to Improve Prostate Cancer  
Screening and Follow-up in a Small Urban Community**

IRB# Protocol #1243-99-7ER

You are being asked to voluntarily be part of a research study in the School of Nursing, Duke University Medical Center. You are being asked to participate in focus group discussion about African American men's concerns about their health. You will be one of approximately 10 men who will be asked to participate in this discussion group.

This discussion group is a study about how men make decisions to seek and follow up on health care issues. This study is funded by a grant to the Duke University School of Nursing, Durham, North Carolina, from the United States Army Medical Research and Materiel Command.

Dr. Price would like to include you as one of the men in the discussion group called a "focus group". She would like to get your thoughts on health care in general as well as health care for African American men 40 years of age and older. A man will conduct the discussion group. Dr. Price hopes to learn how to help other men figure out ways to get better health care for prevention of male health problems, especially problems of the prostate gland.

Men are being recruited for this study through three church congregations of differing sizes. The men will represent African American men 40 years of age and older who come from all sections of the Durham community. A total of 42 to 60 men will be recruited across income levels to participate in the focus groups. Two additional focus groups are being recruited from men's organizations or clubs representing various sections of the Durham African American community, and one group is being recruited from a Durham city barber shop with a large number of adult male customers. A two-person male team, consisting of a group facilitator and note taker, will conduct the focus groups. Informed consent will be obtained from the focus group participants prior to the conduct of the group. Discussions will be recorded using two tape recorders simultaneously (for back up).

What you and everyone in the group have to say is very important, so Dr. Price would like this session recorded on tape, and the leader will take notes on paper. If you want to have the tape recorder turned off for a while during the focus group, just say so. The summary information will be taken off the tapes and notes without identifying individuals, and the original tapes and notes will be secured of access only by Dr. Price. What each person says during this discussion is confidential. The audiotapes will be destroyed at the study's end.

There are no known risks to being in this group discussion. Although there are no direct health benefits to you, there is the possibility that men here can help each other take steps toward

Initials of Participant \_\_\_\_\_

Initials of Witness \_\_\_\_\_

**Consent For Research**

**CONSENT FOR FOCUS GROUP PARTICIPATION**

**Using a Tracking System to Improve Prostate Cancer  
Screening and Follow-up in a Small Urban Community**

IRB# Protocol #1243-99-7ER

more positive health care. Also, information gained from the study will be shared with health care providers in the Durham area because in the future what we learn may help health care providers in your community know how to better meet men's needs for early prostate cancer detection. It is not expected that any discussion in the group should cause risk or discomfort. However, should any unforeseeable risks and discomforts arise, counseling will be available for the individual.

The guidelines for conducting of the group will be reviewed with you. These guidelines include: (1) each person is to speak one at a time; (2) it is alright to disagree with what someone else says; however, please listen quietly to what others say and respect their opinion; you may then add your comments and opinion; (3) try not to make unnecessary sounds or noises, such as tapping your finger or tapping a pencil on the table, or sliding your chair. The extra noises interfere with the recorded conversation on the tape recorder and sound louder than they really are when the tapes are played back ; (4) no eating, drinking, or smoking during the focus groups. Refreshments will be provided after the group has ended. Smoking can take place outside the building. If you do not understand the guidelines, either the note taker or group facilitator will take you aside and re-explain the guidelines for conducting the group to you. If you continue to be unable to follow the guidelines, you will be asked to leave the group.

You can refuse to answer any question, and you can leave the group at any time. Participation in this study is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue your participation at any time without penalty or loss of benefits.

The focus group session will last about 1 ½ -2 hours. At the end of the group meeting, you will be given \$25 for participating. You are responsible for getting yourself to and from the group.

All records for this study will be stored in locked files in the office of Dr. Price at Duke University School of Nursing, and access will only be permitted by Dr. Price and the study personnel.

Initials of Participant \_\_\_\_\_  
Initials of Witness \_\_\_\_\_

**CONSENT FOR RESEARCH  
CONSENT FOR FOCUS GROUP PARTICIPATION**

**Using A Tracking System To Improve Prostate Cancer  
Screening And Follow-Up In A Small Urban Community**

IRB # Protocol #1243-99-7ER

It should be noted that representatives of the U.S. Army Medical Research and Materiel Command are eligible to review research records as a part of their responsibility to protect human subjects in research.

There are no precautions that are expected from participating in the focus group discussion. However, should you have concerns, please contact Dr. Price or the Group Facilitator.

If you have questions now or later, you are welcome to call Dr. Price or contact the Group Facilitator who can be reached through Dr. Price's Office :

Dr. Marva Price    Office: 919-684-3786 extension 245

Initials of Participant \_\_\_\_\_

Initials of Witness \_\_\_\_\_

Participant's Permanent Address (*please print*):  
\_\_\_\_\_  
\_\_\_\_\_

Name of Witness (*please print*)  
\_\_\_\_\_

Permanent Address of Witness (*please print*):  
\_\_\_\_\_  
\_\_\_\_\_

DUKE UNIVERSITY MEDICAL CENTER  
SCHOOL OF NURSING

## CONSENT FOR RESEARCH

### Using A Tracking System To Improve Prostate Cancer Screening And Follow-Up In A Small Urban Community

#### CONSENT FOR FOCUS GROUP PARTICIPATION

IRB # Protocol #1243-99-7ER

When results of a study such as this are reported in nursing, medical and health care journals or at meetings the identification of those taking part is withheld.

"I have read the attached information and have been given the opportunity to discuss it and ask questions. I have been informed that I may contact Dr. Marva Price (919-684-3786) to answer any questions I may have during the discussion. I may also contact the Duke University Medical Center Office of Risk Management at 919-684-3277 for any questions concerning my rights as a focus group participant. I agree to participate, knowing that I may leave the group at any time."

Participant's Signature \_\_\_\_\_ Date \_\_\_\_\_

Signature of Person  
Obtaining Consent

\_\_\_\_\_  
Date \_\_\_\_\_

Initials of Participant \_\_\_\_\_

Initials of Witness \_\_\_\_\_



**Consent For Research**  
**CONSENT FOR FOCUS GROUP AUDIOTAPING**

**Using a Tracking System to Improve Prostate Cancer  
Screening and Follow-up in a Small Urban Community**

**IRB# Protocol #1243-99-7ER**

You are being asked to give permission for audiotaping of this focus group session.

What you and everyone in the group has to say is very important, so Dr. Price would like this session recorded on tape and the leader will take notes on paper. If you want to have the tape recorder turned off for a while during the focus group, just say so. The summary information will be taken off the tapes and notes without identifying individuals, and the original tapes and notes will be secured of access only by Dr. Price. What each person says during this discussion is confidential. The audiotapes will be destroyed at the study's end.

There are no known risks to being in this group discussion. Although there are no direct health benefits to you, there is the possibility that men here can help each other take steps toward more positive health care.

If you have questions now or later, you are welcome to call Dr. Price or contact the Group Facilitator who can be reached through Dr. Price's Office :

Dr. Marva Price    Office: 919-684-3786 extension 245

Participant's Signature:

\_\_\_\_\_

Date: \_\_\_\_\_

Participant's Permanent Address:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Initials of Participant ... \_\_\_\_\_

Initials of Witness ... \_\_\_\_\_

Name of Witness (*please print*)

\_\_\_\_\_

Signature of Witness

\_\_\_\_\_

Date: \_\_\_\_\_

Permanent Address of Witness  
(*please print*):

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**MEN'S FOCUS GROUP**

GROUP \_\_\_\_\_ DATE \_\_\_\_\_

1. DATE OF BIRTH  
(MONTH/DAY/YEAR)

2. ARE YOU?

- ☐ married  
☐ never married  
☐ widowed  
☐ divorced  
☐ separated

3. WHAT IS THE KIND OF  
WORK YOU DO MOST OF  
THE TIME (OR USED TO DO  
IF YOU ARE RETIRED)?

4. CONSIDERING YOUR AGE,  
HOW WOULD YOU  
DESCRIBE YOUR  
OVERALL HEALTH?

- ☐ excellent  
☐ good  
☐ fair  
☐ poor

5. DO YOU HAVE A FAMILY  
DOCTOR?

- ☐ No  
☐ Yes

6. HOW LONG HAS IT BEEN  
SINCE YOU WENT TO SEE  
YOUR HEALTH CARE  
PROVIDER FOR ANY KIND  
OF HEALTH CARE?

7. HAVE YOU EVER HAD A  
PROSTATE EXAMINATION?

- ☐ NO  
☐ DON'T KNOW  
☐ YES

8. IF YOUR ANSWER WAS YES,  
IN WHAT YEAR WAS YOUR  
LAST PROSTATE EXAM?

9. WHAT IS YOUR HIGHEST LEVEL  
OF EDUCATION?

- ☐ Grade School  
☐ Some High School  
☐ High School Graduate  
☐ Some Technical School  
☐ Technical School Graduate  
☐ Some 4 Year College  
☐ 4 Year College Graduate  
☐ Some Graduate School  
☐ Graduate School or Professional  
School

THANK YOU

DRAFT MANUSCRIPT

Free Community Prostate Cancer Screening: Who Attends and Why?

Marva Mizell Price, DrPH, MPH, RN  
Duke University School of Nursing  
Durham, N.C.

The views, opinions and or findings contained in this report are those of the author and should not be construed as an official Department of the Army position, policy or decision.

## ABSTRACT

**Journal:** Oncology Nursing Forum

**Title: Free Community Prostate Cancer Screening: Who Attends and Why?**

This manuscript will describe the results of a year-long study about men who participated in free prostate cancer screening clinics. The study was funded by the United States Department of Defense.

**Purpose/Objectives:**

This study developed a prostate screening tracking system for men who attended either of two mass screening clinics in a small urban community in 1998 and 1999.

- To organize screening data to determine characteristics of men who attend free mass screening clinics
- To describe how those men with abnormal results (digital rectal examination or prostate specific antigen) make decisions to or not to follow-up with their health care provider following notification of abnormal test results

**Design:** This study was primarily survey and qualitative focus groups.

**Setting:** Community based; this study was conducted in a small urban community - Durham, North Carolina

**Sample:** A total of 902 prostate cancer screening visits over two years for men living in or near Durham, North Carolina, of various income groups, over the age of 40, and primarily White and African American.

**Methods:** Consent to participate in screening was obtained; participants completed a survey. On the consent form, they indicated if they would accept a follow-up telephone call about their results, pending any abnormality in the digital rectal examination and/or the Prostate Specific Antigen Test. Ten months following the screening clinics in each study year, telephone interviews were attempted to 183 participants.

**Main research variables:** demographic variables

**Findings:** The number of men who were screened in the two years, according to race and ethnicity, found White men at 50.50% and 57% in 1998 and 1999 respectively. For African American men, participation in the study was 47.3% and 41% for the same respective years. The sample for 1998 and 1999 showed a profile of men who attend free mass prostate cancer screening who are primarily older, better well-educated, and in upper levels of employment. Among the study participants, motivating factors to seek screening included encouragement by a spouse or loved one, early detection, peace of mind, to preserve health, and half had a relative affected by prostate cancer.

**Conclusions:** In this urban sample, participants tended to be men 40 years and older who were likely to be better educated and employed. Motivation for follow-up of abnormal results included wanting their personal physician to see the results, to get a repeat PSA or digital rectal exam, or to get a referral to an urologist. For men who did not pursue follow-up, reasons given included a need to wait for a year to see if the number increased (the PSA result did not 'sound like' a high number to them), and they did not feel 'bad' (experience symptoms that might indicate a problem). A few men said they just never got around to talking to a physician about their results.

Free prostate cancer screening tends to be more attractive to men who are generally well informed, and who already may have health care coverage. This study provided useful information on who attends mass screening clinics in this particular urban community, and how men use the results for early diagnosis and treatment of prostate cancer when warranted.

**Implications:** Nurses are in a unique position to inform and provide information to individuals and families about prostate cancer screening, so that men can make personal informed decisions about seeking prostate cancer screening, whether in mass screening settings, or with individual health care providers. Innovative strategies must be designed to encourage men who are less well educated and in non-professional employment to seek prostate cancer screening.

The views, opinions and or findings contained in this report are those of the author and should not be construed as an official Department of the Army position, policy or decision.

## INTRODUCTION

In the United States, prostate cancer has become the second most commonly diagnosed cancer in men after skin cancer, and the second most common cause of male cancer death exceeded only by lung cancer. It accounts for almost as many deaths among men as breast cancer among women (ACS, 2000; National Cancer Institute, 2000). Prostate cancer is the fourth most commonly diagnosed cancer in men worldwide. However, the mortality from prostate cancer is generally highest in Western countries than in developing countries of the Middle East or Asia.

It is estimated that in 2001 in the United States 180,400 new cases of prostate cancer will be diagnosed and 31,900 deaths will occur (ACS, 2000; Landis, Murray, Bolder, 1999). However, prostate cancer is a disease in which the incidence and mortality rates vary significantly according to race and ethnicity. Mortality among African American men from prostate cancer is among the highest in the world with a rate of 53.7 per 100,000.

Within the United States the differences in prostate cancer incidence and mortality are startling. The incidence of prostate cancer in African American men is estimated to be as much as 66% higher than among age-matched White men (Eyre, 1997). Between 1990 and 1995, the incidence rate among African American men was highest at 224.3 per 100,000 compared to White men at 150.3; Hispanic, 104.4; Asian/Pacific Islander, 82.2; and American Indian, 46.4. The mortality rate for this disease is also dramatically two-fold higher among African American men versus the highest mortality rate of other racial and ethnic groups (Bozeman, et al., 2000; Powell, et al., 2000).

Despite its prevalence, the natural history of prostate cancer is remarkably heterogeneous. In many men, the cancer progresses slowly, resulting in moderately or poorly differentiated

tumors that remain localized to the prostate gland. Although potentially life threatening, such cancers are often curable. In other men, however, tumor growth is rapid and can spread beyond the confines of the prostate, usually to the bone. Early diagnosis is essential because the majority of prostate cancer diagnosed by the prostate specific antigen or PSA (85%-90%) is rapid growing and, if left untreated, would most likely progress. (Elhilali, 2000; Fleshner, Rakovitch, & Klotz, 2000; Hankey, et al., 1999). In such cases, the cancer is not curable, and long-term survival is considerable diminished. Strategies for managing prostate cancer, therefore, have been aimed at early detection and local treatment of the cancer (Anonymous, 2000). With early detection through screening and timely treatment, nine out of ten men will survive a minimum of five years. However, with late diagnoses, only three of ten men will have a 5-year minimum survival rate (Tingen & Weinrich, 1998).

The conceptual framework for this study was based on the Health Belief model (HBM; Rosenstock, 1988). The HBM is one of the most widely recognized conceptual frameworks of health behavior. The premise underlying the model is that individuals fear the threat of a health problem. A person's motivation and confidence to activate readiness for action are based on one's perception of the degree of the perceived threat. However, perceived barriers and benefits mediate those actions.

Relatively little is known about the characteristics of men who attend free prostate screening clinics, what motivates them to attend the clinic, and how they make decisions to follow-up when they have abnormal findings from the screening. In the present study, three major research activities were conducted. First, a database of annual screening participants was developed. From the database, the characteristics of men who voluntarily participated in free prostate cancer screening were examined. Second, participants with abnormal findings on

screening were telephoned to determine if they sought follow-up care and how they made their decisions to follow-up on those results. Third, focus groups were used to hear first-hand the concerns and attitudes of African American men about prostate cancer screening and to increase African American men's awareness about early detection of the disease.

#### Background Information on the Free Mass Screening Clinics

The sponsorship of the free mass prostate screening on which this study was based was not part of this study. However, data from the clinics was provided for this study. Free mass prostate screening was began nearly ten years ago by an urologist at a major medical center in a small urban southern city. Free prostate cancer screening has been offered annually to men 40 years and older, regardless of racial background or ability to pay. The free clinic was conducted in the fall of each year to coincide with Prostate Cancer Awareness Week. In 1997, an additional clinic was added at a community health center, which is centrally located in a primarily African American residential area of the inner city. The sponsor of the free clinics recognized that few African American men participated in the free screening day. The inner city site was added to attract African American men to screening. Historically, this comprehensive health center primarily has served low-income African American families.

Information publicizing the free clinics included flyers in the community in various public agencies, churches, medical clinics, physician offices, and public clinics, the main city newspaper and the local African American newspaper, television, and radio public service announcements. A mailing list was purchased that contained approximately 25,000 names and addresses of men in the city who were 40 years of age and older and a flyer announcing the free clinics was mailed to each individual on the list.



The four-hour clinics were conducted on a weekend day at both clinics. At the community health center, the clinic was conducted in the primary care clinic. Urology attending physicians conducted examinations at both clinics. Also at the community health center, the internal medicine physicians conducted examinations in addition to the urologists. PSA samples were collected by laboratory staff at either clinic and processed in the usual manner for PSA samples at the respective facilities. At both clinics, staff and individuals from the community volunteered to generally assist participants, assist participants with completing forms, and to facilitate orderliness and ease in moving through the stations of the screening clinic. Participants were screened on a first-come, first-served basis. Upon registration, participants voluntarily read and signed a consent form that gave information about prostate cancer, and what screening involved. Participation required their signature along with a witness signature. Participants indicated on the consent form if they could be telephoned regarding any abnormal findings found on screening. Prior to participating in the screening activities, participants completed a Prostate Cancer Screening Questionnaire and a Prostate Health Survey. Requested information on the forms included participant demographic characteristics, family and medical history related to prostate and breast cancer, urinary symptoms, and why the individual sought screening.

Men waited their turn for screening in clinic waiting rooms and hallways. Results of the DRE, either normal or abnormal, were recorded by the physician on the Screening Questionnaire. Whether the exam was normal or abnormal, the man was verbally informed of the results, and given a tear-off with the results. If the exam indicated that the prostate was found to be abnormal indicating a need for further follow up by a physician, the man was instructed to see his physician as soon as possible. When Bilateral Prostatic Hypertrophy (BPH)

was found on the DRE, the physician discussed information about this condition directly with the participant, and gave verbal advice for any further care. When the screening was completed, each participant was provided light refreshments and an information packet with brochures about prostate cancer.

PSA tests were processed and the results were sent by letter to the patient within three months. The letter that stated that their DRE and PSA results were either normal or abnormal and the numerical value of the PSA was stated in the letter. The letter was mailed to the participant's address that he wrote on the questionnaires at the time of screening. If either the DRE or PSA showed abnormal findings, the participant was again instructed in the letter to seek follow up with a physician. The data was placed in storage.

## METHODS

### Sample

This study focused on African American men in a small urban city. In 1998 and 1999, 792 men were screened at a free mass prostate screening at the two sites. Four hundred eighty-five men were screened in 1998 and 419 men were screened in 1999. A total of 904 screening visits were made<sup>1</sup>. The total number of screening clinic visits decreased from year 1998 to 1999, 485 versus 419 in each year respectively. A calculation of duplicate participants in 1999 indicated that 110 men who were seen in 1998 also returned for screening in 1999. From this study data, we cannot measure if men who did not return for screening sought screening elsewhere, such as from their personal health care provider or an urology specialist.

### Screening Database

To create the screening database, data from a Questionnaire and a Prostate Health Survey were coded and entered into an SPSS (10.0) systems file. Data entered into the database

included the following: a database individual identification number assigned to each record, the identification number assigned by the clinic, the participants' name, address, telephone number, date of birth, age in years at the time of the screening, self-reported race, type of work<sup>2</sup>, employment status, highest level of education attained, reason for seeking screening, whether the participant had a regular health care provider, the last time the participant saw a health care provider, whether the participant had a relative or close friend who has had prostate cancer, and the participant's permission to follow up by phone if his screening results were abnormal.

Follow-up Telephone Interview Protocol. Using a semi-structured interview protocol, follow-up telephone calls were conducted to contact participant's who had received abnormal screening results and to discuss whether and why the participant chose to follow-up on his abnormal screening results.

#### Procedure

In 1998, telephone calls were attempted at a six-month interval to each of the participants who had either an abnormal DRE, and/or elevated PSA. Ten months after the screenings took place, over a three-week interval on random days and various times, at least six attempts were made to reach participants. The ten-month interval was based on the assumption that within that period of time, even in a very busy or large clinical practice, a man who intended to follow-up would have been able to get an appointment with his health care provider or an urologist. Identical procedures were followed as described for 1999 for follow-up phone calls in 2000. Each participant's response in the telephone interview about his failing to seek further medical advice was summarized, categorized by the theme of his discussion, and entered into the study database.

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<sup>1</sup> This number includes 110 participants who were screened both years.

### Analysis

Frequencies, means, and standard deviations were used to examine the distribution of participant's responses in each category. T-tests were used to examine differences between groups of participants. All analyses were conducted using SPSS (10.0). Because the data were mostly self-report data, some participants chose not to report information that they thought was too personal or too revealing (e.g., date of birth, age, race, education, etc.). Missing data was considered missing at random. Therefore, analyses used the valid sample size excluding missing data.

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<sup>2</sup> Employment descriptions were taken from the questionnaires and categorized according to the Department of Labor job classifications (Dictionary of Occupational Titles, 1991, Department of Labor).

## RESULTS

Demographic Characteristics of Free Screening Participants

Overall, 792 men were screened at a free mass prostate screening held at two sites in 1998 and 1999. The average age of the men screened was 58.74 years (s.d.=11.76), with a range of 25 to 99 years of age. There was a significant difference in age at screening between African American and White men ( $t=-8.77$ ,  $p<.001$ ). African American men were significantly younger at screening than White men were (54.80 years versus 62.22 years, respectively). Among the men screened in both 1998 and in 1999, African American men were significantly younger at screening than White men ( $t=-6.81$ ,  $p<.001$ ;  $t=-6.48$ ,  $p<.001$ , respectively).

Of the men who reported their race, more than 45% (346/765) of the men screened were African American, 52.4% (401/765) were White, and 2.4% (18 of 765) were other racial and ethnic groups. Specifically, in 1998, 231 White men (50.50 %), 215 African American/Black men (47.30 %), and 18 men of other races (2.20%) were screened. In 1999, 419 men were screened: 231 White men (57.00%), 166 African American/Black (41.00 %), and 8 men of other races (2%).

Of the total sample, slightly more than half of the men (422 of 744) reported that they were still employed. Of those not employed, the majority was retired. The majority of the screening participants reported having attained a high school diploma, having a family doctor, and having visited a doctor for health within 12 months of the screening.

Demographic predictors for participation in free prostate cancer screening were race, age, employment, education, and use of health care (having a family doctor or visited a doctor). By racial breakdown, African men were more likely to be less well educated and employed in non-

professional jobs. African American men were equally likely to seek free screening at either screening site. Approximately 53.8% of African American men who participated in screening (1998 and 1999) screened at the community health center, whereas 46.2% screened at the medical center. Of the two hundred sixty-eight screenings that took place at the community health center, 18.7% of the men screened were White, 76.1% were African American, and 5.2% were from other racial backgrounds.

White men, however, primarily sought screening at the free clinic offered at the medical center. Approximately 89% of White men screened at the medical center, while 10.9% screened at the community health center. Of the 618 total screenings that took place at the medical center, two-thirds were of the men screened were White, 28.3% were African American, and the remaining men were of other racial backgrounds.

1998 and 1999 screening participants were primarily older men, better well educated, and in upper levels of employment. Thirty-four percent were in professional careers while 30% were in middle level management; and 19% were in industry and trade careers. The remaining did not indicate their types of employment. These findings showed a higher level of education and employment than found in other studies of mass screening (Barber, et al, 1998; Weinrich, 1998).

Three hundred sixty-seven men (47.5%) reported having a relative or close friend who had or has prostate cancer. Roughly half of White men (202 of 392) reported having a relative who had or has prostate cancer. Similarly, 43.7% of African American men (150 of 343) reported having a friend or relative with prostate cancer.

At least 525 men (68.4%) men indicated that they had used health care. This item was not specific to having been screened for prostate cancer. Of the total number of men screened in the

study, approximately 68% had a regular family doctor and reported visiting a doctor within the past two years.. For African American men, 209 (62.0%) had a family doctor. Almost 75% of White men had a family doctor (331 of 395 men). The majority of the men screened also reported visiting a doctor for health within 12 months of the screening. 83.8% of White men and 87.6% of African American men reported having visited a doctor within two years of the screening.

#### Motivating Factors to Attend the Free Clinic

Among the study participants, motivating factors to seek screening included encouragement by a spouse or loved one, early detection, peace of mind, to preserve health, and 47.5% had a relative or friend affected by prostate cancer. The finding 'to preserve health' is consistent in other studies that show across the board, that African American men are concerned about their general health and general health maintenance (Scroggins & Bartley, 1999).

#### Follow-up Examinations of Abnormal findings

Background research for this project did not find any examples in the scientific research literature regarding intend to follow-up for men who had participated in mass screening for prostate cancer. One hundred percent of the men who were reached consented to the follow up interview. One hundred eighty three participants had either (or both) an abnormal prostate or elevated PSA. The number of abnormal tests was 74, 39, and 70 in 1998, 1999, and 2000 respectively. Fifty-four men sought follow-up care<sup>3</sup>.

### DISCUSSION

#### Screening for Prostate Cancer

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<sup>3</sup> Upon follow up, it was discovered that two men died from causes apparently unrelated to prostate disease. Their wives did not indicate that they had followed up on their abnormal screening results.

A PSA and DRE were used in the mass prostate cancer screening clinics upon which this study builds. Of the screening tests for early prostate cancer, only the PSA tumor marker blood test stands out as both convenient to administer and potentially sensitive enough to detect prostate cancer while it is localized to the prostate gland (Merrill, & Stephenson, 2000). In a recent study Labrie and colleagues (1999), compared the prostate cancer mortality rates between 1989 and 1996 of men who were screened for PSA with those who were not. They found that early diagnosis and treatment through PSA screening resulted in a dramatic decrease in deaths from prostate cancer. As many as 20% of men with normal PSA test results may be diagnosed with prostate cancer by a DRE. There is general agreement that the DRE also fails to identify a substantial proportion of men with prostate cancer. Thus, the use of both tests leads to the best detection of prostate cancer.

However, not all who are concerned with prostate cancer diagnosis and treatment support screening. The role of PSA as a screening test for prostate cancer is controversial, and professional medical organizations are divided on the issue of screening for prostate cancer. Proponents of screening emphasize that early detection can lead to discovery of organ-confined disease and the potential for cure. Opponents point to the lack of credible evidence that screening is associated with decreased mortality (McNaughton, Collins, Stafford, & Barry, 2000). Despite scientific controversy about the appropriateness of mass prostate cancer screening among population groups, the American Cancer Society (ACS 2001), National Medical Association, American College of Radiology, and American Urological Association (1992), recommend that annual DRE screening begin at age 40 for asymptomatic men; and DRE and PSA at age 50 for asymptomatic men, even without family history. They recommend that screening start at age 40 for men of African descent and for men with a family history of



prostate cancer. In contrast, a lack of consensus on PSA screening is reflected in the diversity of recommendations from other medical and physician organizations. For example, in 2000, the American Medical Association voted against adopting screening guidelines on PSA at age 50. The U.S. Preventive Services Task Force (1996) only recommends PSA/DRE screening for men with life expectancies of at least 10 years. The American College of Preventive Medicine does not recommend routine screening for prostate cancer with DRE or PSA (Harris, et al 2001; Woolf, 2001).

Prostate cancer screening with the PSA is recommended by several professional organizations, and it has become standard in many medical practices. There is less consensus, however, about the level at which an additional course of action should be recommended once a PSA test has been done. Although a serum level between 0 ng/mL and 4.0 ng/mL PSA is considered normal, it has been suggested that the upper limit of normal (i.e., 4 ng/mL) might be too high, particularly for younger (i.e., 45-55 years of age) men where the prostate size is small, and that any results above 2.5-3.0 ng/mL might warrant a referral to a urologist (Elhilali, 2000). Other recent randomized studies also demonstrate that treatment of localized prostate cancer saves lives. With appropriate screening 92%-99% of prostate cancers can be diagnosed at the localized stage with no signs of bone metastases (Labrie, 2000). Available data show that an increase in acceptance and participation in regular PSA/DRE screening can markedly reduce mortality.

#### Characteristics of screening participants

Frank-Stromborg, 2000, previously described community based screening in rural Illinois. Our findings differed slightly from Frank-Stromborg's work. Our population consisted largely of White men older than 50 (73.7%), educated, and currently or before

retirement likely to work in skilled occupations. Frank-Stromborg's more rural population primarily consisted of men who were between the ages of 40 and 60 (69.8%), White (91.4%), employed in a profession (30%) or in a service occupation (20.9%), and they did not have a relative with prostate cancer (75.2%). The mean age for our population was 58.74 years.

Twenty men between the ages of 25 and 39 participated: 14 of them were screened in 1998, and one was screened in 1999. Frank-Stromborg's rural Illinois population had a mean age of 58.6, which is almost identical to the mean age for our study participants. Experts have found that prostate cancer tends to occur more frequently in African men, often at a younger age than in White men, and the cancer can be a more aggressive disease. Experts can't agree, however, that the optimal age to screen African American men is 40 years versus 50 years of age (Brawley, Knopf, & Merrill, 1998; Gerard, & Frank-Stromborg, 1998).

Weinrich, (1998; 2000) and Tingen, 1997 studied prostate cancer screening participation among African American men, and found the significant demographic predictors were race, age, and income. In the Weinrich study, African American men were less likely to go for screening than White men were, and participation increased as age increased. Men with lower family incomes were less likely to be screened, and marital status (being married) positively influences screening. While marital status was not measured in this study, men often cited that the encouragement of a spouse or loved one encouraged them to get screened.

#### Follow Up of Abnormal DRE and PSA test results

There is a dearth in the literature on the follow up aspect of mass prostate cancer screening. Myers et al (2001) conducted telephone interviews with 413 African American men in Philadelphia. The men were hospitalized for reasons unrelated to prostatic disease and were not

being screened for prostate cancer. They were asked about their intent to follow up on abnormal findings if at some future time they were to undergo a PSA test. Eighty-six percent said that they thought they would follow-up. In contrast, in this study, the focus was on men who actually underwent screening. This study summarized each man's response about why he had not taken the results of his tests to a physician for follow up. Reasons given for not engaging in follow up included a personal decision to wait for a year to see if the number increased (*the PSA result did not sound like a high number to them*), and they did not feel 'bad' (*meaning that they did not experience symptoms that might indicate a problem*). Some men said they just never got around to talking to a physician about their results. During the study telephone interviews none of the men cited economics (lack of health insurance, no source of care) as reasons why they did not follow-up. In Weinrich's work (2000), six barriers were found to be more significant in predicting initial participation in prostate cancer screening: Put it off, doctor hours not convenient, didn't know kind of doctor, didn't know where to go, and refuse to go. Women have been shown to worry when they have abnormal test results (Lerman, & Rimer, 1993; Lipkus, Halabi, Striago, & Rimer, 2000). However, none of the men reached by telephone cited "worry" as a reason that they did not take their abnormal results to a physician for follow-up. The number of men who chose to follow-up on abnormal test findings was dissimilar between years 1998, 1999, and 2000. Since different numbers of men who followed up had been screened in the previous year, it is unknown what other factors may have influenced their desire to follow up.

Failure to determine whether a participant had followed up on abnormal results included: wrong phone number, the phone number was disconnected; moved to another city-address unknown; the participant was never at home when contact was attempted; or another person at

the household answered and seemed hesitant to give the participant a message to return a call to the study investigator, and the participant's death.

#### Motivation for Screening

The findings in our study were consistent with other studies reported in the literature. For example, 'to preserve health' and concern expressed about their general health and general health maintenance has been frequently cited by African American men (Scroggins, & Bartley, 1999). Investigators have found that among women, physician recommendation is strongly related to cancer screening. This variable was not measured in this study, however, a large number of men who were screened had access to health care which was indicated by their responses to questionnaire items: *"Do you have a family doctor?" And, "When was the last time you went to see a doctor for anything about your health?"*

## DISCUSSION

This study has added to the limited scientific knowledge about attendance at free screening clinics. Nearly all of the previous study on mass screening has been conducted by nurse researcher Weinrich and her colleagues. Those works were conducted over the latter portion of the past decade. As clinicians and medical practitioners strive for consensus on prostate cancer screening, continued research contributions are needed to address men's screening behavior, especially for prostate cancer prevention among minority men. Further research inquiry is needed to examine issues that promote sustained screening. A major concern raised by this study is the number of men (375) who did not return for screening in the subsequent year. Where did they go for screening? For those with abnormal results, how could they be adequately motivated to follow up with an appropriate health care provider?

Results show that innovative and culturally sensitive strategies must be designed, especially to encourage African American men who are less well educated to seek prostate cancer screening. There is a need for information about prostate cancer and prostate cancer screening among men and their significant others and families, especially for men in lower income levels and those in less skilled and professional employment areas.

The controversy about who and at under which conditions to screen needs consensus building. However, while differences remain among cancer and policy organizations and professional groups, individual physicians can help each of their male patient's make the best informed decision about annual screening, based on their risk factors and general health. Low-cost, accessible community screening should be promoted among African American men to close the gap in morbidity and mortality from prostate cancer. More research inquiry is needed

to address the health disparity that remains for prostate cancer, particularly for African American men.

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## Oncology Nursing Forum

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August 23, 2001

Marva Mizell Price, DrPH, MPH, RN  
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Dear Dr. Price:

Thank you for your letter inquiring about our interest in a manuscript entitled "Free Community Prostate Cancer Screening: Who Attends and Why?". The manuscript appears to be very interesting and, in light of our interest in both prevention and detection and culturally competent nursing care, we would be interested in receiving this manuscript for peer review. Should you need it, a copy of our author guidelines is enclosed.

If I can be of any assistance to you in the preparation of this manuscript, please don't hesitate to give me a call.

Sincerely,

Rose Mary Carroll-Johnson, MN, RN  
Editor, *Oncology Nursing Forum*

RM CJ/nsat

Enclosure

Published by the Oncology Nursing Society

## Appendix L: STUDY PERSONNEL

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Department of Maternal and Child Health and the Public Health Leadership Program.

Fellow, Lineberger Comprehensive Cancer Center, University of North Carolina School of Public Health, Chapel Hill. Dissertation Title: Generational Influences on Cervical Cancer Screening and the Capacity of the Public Health System to Assure Responsive Services.

M.P.H. (Maternal Child Health), University of North Carolina, Chapel Hill, 1974.

B.S. (Nursing) Magna Cum Laude, North Carolina Agricultural and Technical State University, Greensboro, North Carolina, 1972.

Family Nurse Practitioner Certificate, University of North Carolina at Chapel Hill, School of Nursing, 1974.

**LICENSURES and CERTIFICATIONS:**

Family Nurse Practitioner Eligible Approved to Practice - North Carolina Board of Medical Examiners.

Registered Nurse Licensure in North Carolina.

American Nurses' Association Certified Specialist as Family Nurse Practitioner.

Natural Family Planning Instructor. Certified, St. Margaret's Hospital, Boston.

**ADDITIONAL COURSE WORK:**

Norplant System Insertion Training, Association of Reproductive Health Professionals of Washington, D.C.

Family Planning for Family Nurse Practitioners, Emory University Regional Training Center for Family Planning, Atlanta.

Post-Master's Program in Nursing of the Handicapped Child and Developmental Disabilities, University of Washington, School of Nursing, Child Development and Retardation Center, Seattle, Four-Summer Sequence Completed.

Principles and Practice of College Teaching, University of North Carolina at Chapel Hill.

**ACADEMIC APPOINTMENTS AND EMPLOYMENT:**

- Promotion to ASSISTANT PROFESSOR, June 2001.
- ASSISTANT CLINICAL PROFESSOR, School of Nursing, Duke University, Durham. 8/1996-. Faculty appointment in the Master of Nursing Family Nurse Practitioner Program.

- ADJUNCT ASSISTANT PROFESSOR, School of Nursing, University of North Carolina at Chapel Hill. Fixed term appointment 1976-.  
Part-time faculty Spring 1997 and 1998 for PHCY 167.
- ADJUNCT ASSISTANT PROFESSOR, Department of Maternal-Child Health, School of Public Health, University of North Carolina at Chapel Hill. 1976-1983. Provided select graduate lectures and mentorship.

#### **OTHER EMPLOYMENT:**

- FAMILY NURSE PRACTITIONER (part-time), Randolph County Health Department (Asheboro), Summer 1996. Provided women's family planning and acute gynecology services.
- FAMILY NURSE PRACTITIONER (part-time), Kaiser Permanente, Durham-Chapel Hill Office, Summer-Fall 1994. Health Evaluation Program and management of acute illnesses.
- NURSE PRACTITIONER AND PROGRAM COORDINATOR FOR THE WOMEN'S COMPREHENSIVE CANCER SCREENING PROGRAM, Department of Obstetrics and Gynecology, Division of GYN Oncology, Duke University Medical Center, Durham, NC. November 1991-June 30, 1994. Coordination of a preventive health and cancer screening program for well women plus an ovarian cancer screening study. Through interview, provided each woman with a comprehensive risk assessment, exam, and personalized counseling and contracts. In addition, coordinated the Colposcopy Clinic for diagnosis, treatment, counseling, and follow-up of women with abnormal pap smears and other abnormal cervical pathology.
- NURSING CONSULTANT for STATEWIDE WOMEN'S PREVENTIVE HEALTH BRANCH, Division of Maternal Child Health, Department of Environment, Health, Natural Resources, State of North Carolina, Raleigh. Promotion (Spring 1991) to a newly created position. Specialist in family planning and women's care to provide technical assistance to regional nursing consultants, and the 100 county health department nursing administrators. Areas of expertise included program management, clinic efficiency, consultation for medical practice of nurse practitioners and physician assistants, and consultation to local public health staff for development and management of programs for adolescent and teen pregnancy prevention, and adolescent health.
- NURSING CONSULTANT FOR MATERNAL CHILD HEALTH, Department of Environment, Health, and Natural Resources, State of North Carolina. 1982-1991. Responsible for 16 county area (North Central Regional Area, Winston Salem) family planning program consultation on program management, monitoring for quality of care for service delivery, clinic efficiency, and family planning operations. A major focus was adolescent pregnancy prevention. With \$1.5 million legislated by the North Carolina General Assembly for pregnancy prevention each year, was responsible for proposal reviews from local communities, team work for project selection, negotiation for projects parameters, and periodic monitoring of individual projects.
- CLINICAL NURSE SPECIALIST, Division for Disorders of Development and Learning, Biological Sciences Research Center, University of North Carolina at Chapel Hill, 1976-1982. Member of an interdisciplinary team for the evaluation of children with special problems of growth and development. While the program evaluated children, it had a training emphasis on the training of graduate candidates in various health disciplines. In addition to team involvement, provided medical care to pediatric clients who were seen for isolated and more specific medical problems and developmental issues.

- FAMILY NURSE PRACTITIONER, Employees Health Services, University of North Carolina, N.C. Memorial Hospital, Chapel Hill. 1974-1976. Responsible for comprehensive acute care (outpatient) of hospital and medical school employees. This included annual physical exams and preventive laboratory measures such as chest x-rays, tuberculin skin tests, immunizations, and other routine measures for disease prevention and detection. This included diagnosis of illness, laboratory studies to aid in the diagnosis or prognosis, prescription of medications, wound care, and follow-up to determine readiness to return to work. On occasion, seriously ill employees were admitted to the hospital from the nurse practitioner exam, assessment, and diagnosis.
- FAMILY NURSE PRACTITIONER, Orange Chatham Comprehensive Health, Orange and Chatham Counties, N.C. 1974. Affiliated with the Department of Public Health Nursing as a Family Nurse Practitioner for the Orange-Chatham Agency. Provided and administered total comprehensive medical care to families and individuals with a variety of acute and chronic illnesses in a very rural community clinic. Also, supervised community health workers (lay team members who bridged the gap between the clinic and the community).
- STAFF NURSE, Annie Penn Memorial Hospital, Reidsville, North Carolina. 1972-1974. Employed in a full-time position following graduation from college. After admission to graduate school, continued in a part-time staff nurse position on weekends and holidays.

#### **ADDITIONAL PROFESSIONAL EXPERIENCE:**

- MEMBER, CORPRENICOUS INSTITUTIONAL REVIEW BOARD (IRB), Cary, N.C. January 2000-
- MEMBER, RESEARCH TRIANGLE INSTITUTIONAL REVIEW BOARD (IRB), Chartered and established by Clintrials Inc., Research Triangle Park, N.C., 1993-97. Review of new research proposals for major pharmaceutical corporations for participant and ethical appropriateness.
- FACULTY, ONCOLOGY NURSES SOCIETY, Chicago. Development of curriculum and training seminars for nurses from across the U.S. The goal of this NIH Grant, which was awarded to a University of Wisconsin faculty member, provides continuing education for nurses in cancer prevention in African American communities.
- INTERIM HEALTH DIRECTOR, Chatham County Health Department, Pittsboro, NC. Fall 1992. Chief Executive Officer in the absence of a permanent director to ensure continuity of leadership in all aspects of operations for an agency with a \$3.1 million dollar annual budget and composed of 115 staff in two locations; served as chair of the Search Committee for a permanent director, and negotiated the hiring and contract process.

#### **HONORS, AWARDS AND HONOR SOCIETY MEMBERSHIPS:**

Community Health Nurse of the Year, North Carolina Nurses Association, 1997.

Alumni Student Award, UNC School of Public Health, awarded 3/96 at the UNC School of Public Health Annual Alumni Conference.

American Nurses Association Ethnic Minority Fellowship, June 1995.

Albert Schweitzer Fellowship, awarded for 1995-1996.

Sigma Theta Tau Honor Society, inducted 1973.

Delta Omega Honor Society in Public Health, inducted 1973.

Lineberger Comprehensive Cancer Center, University of North Carolina, Pre-Doctoral Fellowship, 1995-1996, 1996-1997.

GREAT 100 AWARD for Nursing Excellence in North Carolina for outstanding contributions to the profession of nursing, October 1993.

**SOCIETY MEMBERSHIPS:**

American Nurses Association. District Eleven North Carolina Nurses Association, 1985-present. Secretary, elected Spring 1985 for term 1985-87.

Oncology Nursing Society, Member.

National Black Nurses Association, Member, and the Central Carolina Black Nurses Association, North Carolina affiliate.

Sigma Theta Tau Honor Society in Nursing, member 1974-present.  
Counselor 1978-1980, University of North Carolina, Alpha Alpha Chapter.

**PRESENTATIONS:**

Poster, "Free Community Prostate Cancer Screening: Who Attends and Why?" School of Public Health Minority Health Convergence, university of North Carolina, Chapel Hill, February 16, 2001.

Podium Presentation, American Public Health Association, "Free Community Prostate Cancer Screening: Who Attends and Why?" Boston, November 2000.

Podium Presentation, National Black Nurses Convention, "Follow-up of Men who Participate in a Free Community Day Prostate Cancer Screening". Washington, D.C. August 2000.

Poster Presentation, "Free Community Prostate Cancer Screening: Who Attends and Why?" 11<sup>th</sup> International Conference on Cancer Nursing, "Follow-up of Men who Participate in a Free Community Day Prostate Cancer Screening Clinic", Oslo, Norway. July 30-August 3, 2000.

National Organization of Nurse Practitioner Faculties (NONPF) 26<sup>th</sup> Annual Conference, "Creating a Faculty Research Opportunity with a Community Prostate Cancer Screening Program", Washington, D.C. April 2000.

Presenter, American Public Health Association, "African American Womens' Concerns about Cervical Cancer Screening", Chicago, November 1999.

Presenter, National Organization of Nurse Practitioner Faculties, "Enhancing Nurse Educators' Knowledge Base to Teach their Students Cancer Prevention and Early Detection in African Americans" and "Using the Albert Schweitzer Fellowship Program to Foster Cross-Cultural Experiences for Nurse Practitioner Students", San Francisco, April 1999.

Presenter, Union of International Cancer Care, "Intergenerational Influences on Cervical Cancer Screening", Rio de Janeiro, Brazil, August 1998.



Seminar Speaker, Delta Sigma Theta Chapel Hill Alumnae Chapter, Inc. Community Breast Cancer Awareness Seminar "Breast Health: What African American Women Need to Know: Chapel Hill, NC, October 1997.

Presenter, North Carolina Baptist Ushers Conference on Cancer Prevention co-sponsored by UNC Lineberger Cancer Center and the UNC School of Public Health, "Cervical Cancer", Durham, NC, August 1997.

Poster, Women's Health Issues A Global Nursing Perspective, "Intergenerational Influences on Cervical Cancer Screening", St. Thomas, Virgin Islands, August 1997.

Presenter, 9<sup>th</sup> Annual National Black Graduate Student Conference, "What Your Mother Needs to Know about Breast Health", Research Triangle Park, NC, May 1997.

Luncheon Speaker, Central Carolina Black Nurses' Council, Inc. "Breast Health: What African American Nurses Want to Know: Durham, NC, December 1996.

Presenter, Oncology Nursing Society Post-Conference Seminar at the Annual meeting of the National Black Nurses Association, "Cervical Cancer", Chicago, August 1996.

Presenter, National Black Nurses Association National Conference, "Gynecologic Cancers-Cervical Cancer", Washington, D.C. August 1995.

Presenter, National Black Nurses Association Regional Conferences, "Breast Health", Washington, D.C. February 1995, Philadelphia and Miami, March-April 1995.

Presenter and Moderator, "Living with Genital Herpes: Counseling the Patient", sponsored by Burroughs Wellcome Pharmaceutical Corporation, Research Triangle Park, N.C., October 28-30, 1994.

Faculty, Oncology Nurses Three-Day Symposiums on Cancer in African Americans, "Gynecologic Cancers, particularly Cervical and Breast Cancer", Miami, August 2001; Washington, D.C. May 2001; Houston, January 2001, five symposiums in Milwaukee, fall 1999, summer 1998; Chicago, August 1996; Philadelphia, March 1995; Miami, April, 1995; Atlanta, October 1994; Philadelphia, December 1993; Seattle October 1993; Lexington, KY April 1993; and Pittsburgh, June 1990.

Presenter, "Developing and Using Computer Generated Slides for Oral Presentations", Dissemination Workshop during the Oncology Nurses Symposium on Cancer in African Americans, Atlanta, October 1994.

Presenter, "Cancers That Worry Women the Most and Screening Dilemmas", Annual Spring Symposium for Primary Care Nurse Practitioners, Charlotte, April 1994.

Presenter, Cancer Prevention and Early Detection: Changing Lifestyles in Vulnerable Populations, sponsored by the University of North Carolina School of Nursing, Chapel Hill, February 1993.

Presenter, "Contraception following Pregnancy Induced Hypertension and other High Risk Medical Conditions": Perinatal Nurse Conference, Durham County Hospital Corporation, Durham, May 1991.

Presenter, "Is There an Ideal Contraceptive for the Breastfeeding Woman?" Annual Perinatal Nursing Conference Duke University Medical Center, Durham, May 1989. (Presentation based on independent research project).

Presenter, "Helping Family Planning Patients Stop Smoking", Annual Conference on Women's Health for Nurse Practitioners, sponsored by Emory University, Atlanta, May 1988.

Panelist, Annual Conference on Women's Health for Nurse Practitioners, sponsored by Emory University, Atlanta, May 1986.

#### **RESEARCH ACTIVITIES:**

Principal Investigator, Department of Defense, Using a Tracking System to Improve Prostate Cancer Screening Follow-up in a Small Urban Community, 2000-2001. \$75,000, 12 months.

Principal Investigator, Avon, Inc. Breast Cancer Access Grant for Nurse Practitioners in Nine-County Area in Southeastern North Carolina, awarded October 1997-98. \$75,000 (\$5,000 match by Carson Products (makers of Dark and Lovely Beauty Products), Savannah). Project completed March 1999.

Protocol Development for Resource Assessment of HIV Infected Women (HIV+ pregnant women's access and use of AZT and other social and medical), National Center for Infectious Disease, Division of HIV/AIDS, Surveillance Branch, CDC, Atlanta. Sponsored by the Association of School of Public Health and The Association of Teachers of Preventive Medicine, Academic year 1994-1995. \$23,000.

Principal Investigator (Predoctoral Fellow), NCI sponsored Cancer Control Education Program (CCEP) Research Project through Lineberger Comprehensive Cancer Center, RO1-CA 64060, awarded fall 1995, project grant approx. \$20,000 (Intergenerational Influences on Cervical Cancer Screening). Renewed fall 1996.

#### **PUBLICATIONS AND MANUSCRIPTS:**

Smith, E, Phillips, J. & Price, M.M. (September 2001). Breast and cervical cancer screening and early detection among racial and ethnic minority women, Cancer Nursing.

Price, M. M. (October 2001). Chapter 45 - Health Promotion with african american women. In C.C. Clark, Health Promotions Textbook. Lippincott. In press.

Phillips, J.M. & Price, M. M. (October 2001). Breast cancer screening and detection. In K.Dozier-Jennings, Cancer Nursing. In press.

Brown, S.M. & Price, M.M. (October 2001). Angioneurotic Edema in a 64-Year-Old African American Man with Hypertension. In press.

Price, M.M. (1995). [HIV+ Pregnant Womens' Use of AZT.] Unpublished raw data.

**DOCTORAL DISSERTATION:**

Price, M.M. (1997). Generational Influences on Cervical Cancer Screening and the Capacity of the Public Health System to Assure Responsive Services. Dissertation Abstracts International, (University of North Carolina, Chapel Hill (1997). Microfische No. W4.P9462.1997.

**MANUSCRIPTS IN PROGRESS:**

Price, M.M. Prostate Cancer Screening: Who Attends and Why? Oncology Nursing Forum, manuscript in progress.

Price, M.M. African American Mothers and Daughters Influence on Cervical Cancer Screening. Manuscript in progress.

Price, M.M. Generational Influences on Cervical Cancer Screening and the Capacity of the Public Health System to Assure Responsive Services. Manuscript in progress.

**NON-REFEREED JOURNALS:**

Price, M.M. (1986-1988). Family Planning Nursing, bi-monthly column, Contraceptive Technology Update, American Health Consultants: Atlanta. Column focus was education for nurse practitioners centered on medical and gynecologic issues from a patient centered approach.

Cited in Public Sector NFP Program, (1988). The NFP Reader, 5 (1), Bethesda: KM Associates.

Price, M. M. (1982), Thumbsucking, reviewed in Pediatric Currents, 31 (1).

Price, M. M. (1980), Why Do They Suck Their Thumbs? Baby Talk, 46 (5,) 28-29.

Cited in Contraceptive Technology Update, (1986). Nurses, physicians prefer different postpartum prescription practices, Interview, American Health Consultants: Atlanta. 7 (9).

Price, M. M. (1980). Critique of the Milani-Comparetti Motor Development Screening Test. Physical And Occupational Therapy In Pediatrics. Vol. 1 (1), 32-36.

**PUBLISHED PROCEEDINGS:**

Price, M. M. (1980). Special Populations Sexual Abuse of the Developmentally Disabled, Leadership Training Workshops, Published Proceedings, Debra Kay (Principal Investigator). Bethesda: National Institute of Mental Health, National Center for Prevention and Control of Rape. Training Grant No. T31MH15664.

**PEDIATRIC BOOK CHAPTER:**

Price, M. M.. (1985). Nursing Care of the Child With A Mental Deficiency. In Mott, SR, Fazekas, NS, James, SR (Eds). Nursing Care of Children and Families. 755-783. CA: Addison-Wesley.

**BOOK REVIEWS:**

Price, M. M. (1989). The Invulnerable Child. Anthony, EJ, Cohler, BJ (editors). In Physical And Occupational Therapy In Pediatrics, 3.

Price, M. M. (1988). Children with Handicaps: A Medical Primer. Ed 2. Batshaw, ML, Perret, YM (Authors). In Physical And Occupational Therapy In Pediatrics, 8 (1).

Price, M. M. (1987). Chronically Ill Children and Their Families. Hobbs, N, Perrin, JM, Ireys, HT (Authors). In Physical And Occupational Therapy In Pediatrics, 7 ( 3).

Price, M. M. (1986). Minimizing High-Risk Parenting. Hoekelman, RA., Media, PA (editors). In Physical And Occupational Therapy In Pediatrics, 6 (2).

Price, M. M. (1986). Diagnosis And Management Of The Hospitalized Child. Levy, HB, Sheldon, SH, Sulayman, RF, (editors). In Physical and Occupational Therapy in Pediatrics, 6, (1).

Price, M. M. (1983). Effectiveness of Pediatric Primary Care. O'Shea, J, Collins, (editors). In Physical and Occupational Therapy in Pediatric.

TEXTBOOK REVIEW:

CARE PLANNING POCKET GUIDE. Ed 2. Lederer, et al. Addison-Wesley. 1986.

OTHER:

Price, M. M. Thumb, Finger Sucking Common Behavior. In Caring For Kids, Chapel Hill Newspaper, October 5, 1980, and April 7, 1985.

**PROFESSIONAL ACTIVITIES:**

American Social Health Association, RTP, NC, National Cervical Cancer and Human Papilloma Virus Project Advisory Board, Member, appointed 1998.

Governor's Commission for Health Service, serving second 4-year term. Appointed by Governor Jim Hunt April 1994, reappointed 1999.

Welfare Reform Committee, Chatham County, 1997-98.

Chair, Work Group for Cervical Quality Assurance for the statewide Breast and Cervical Cancer Prevention Program, NC DEHNR. 1993-95. Continue as member of a consolidated Quality Assurance Committee, 1995-present.

National Black Leadership Initiative for Cancer, North Carolina and Durham area affiliate.

National Health Service Corps, Mentorship Program. Selected as a mentor to recruit North Carolina nurses who need support for nurse practitioner education programs. 1992-.

Executive Board Member At Large, Council of Primary Care Nurse Practitioners of the North Carolina Nurses Association, elected Spring 1991-94.

**GRANT REVIEW:**

Member, Adolescent Pregnancy Prevention Program grants team. Grant proposals reviewed and selected annually by the Women's Health Section of NC-Health and Human Services Department for the North Carolina General Assembly through the Commission for Health Services.

**COMMUNITY PROFESSIONAL SERVICE:**

Board of Directors, Central Carolina Community College Small Business Resource Center. Appointed 1992-1994.

Chairperson, Chatham County Board of Health, 1991 - 1993.

Appointed by the Chatham Board of Commissioners 1988-1999. Charter member.

Board of Directors member for three federally funded primary care centers in the counties of Orange, Chatham, and Caswell, in rural North Carolina. 1986-1987.

**VOLUNTEER:**

Trinidad and Tobago, West Indies. Provided preventive health education to adolescents, teens, and young adults in villages on STD, AIDs, and unintended pregnancy prevention, July 1993.

International Student's Host Family Program, University of North Carolina at Chapel Hill. 1978-94. Long term involvement that included matching of students and host families.

**ABSTRACT: NATIONAL ORGANIZATION OF NURSE PRACTITIONER  
FACULTIES (NONPF) 26<sup>TH</sup> ANNUAL CONFERENCE  
WASHINGTON, DC, APRIL 2000**

**Marva Mizell Price, DrPH, MPH, BSN, FNP, CS  
Duke University School of Nursing, Durham, N.C.**

**CREATING A FACULTY RESEARCH OPPORTUNITY  
WITH A COMMUNITY PROSTATE CANCER SCREENING PROGRAM**

This presentation will describe how the tracking of a free community prostate screening program developed into an opportunity for faculty research.

Prostate cancer continues to rise in the United States and even at a faster rate for African American men than for White men, for reasons that are not clearly understood. This project developed a prostate screening tracking system to provide systematic follow-up for all men with abnormal PSA's (Prostate Specific Antigen Test) and DRE's (Digital Rectal Examination) who attended either of two annual mass screening clinics. Further, factors were determined that predict which men might seek prostate cancer test screening. The ultimate goal is to increase the number of men, regardless of ethnicity, who seek prostate cancer screening, including both the PSA and DRE tests, and accept follow-up services.

The project organized screening data on over 800 men who received free screening in 1998 and 1999. Data was collected from questionnaires and telephone interviews. An analysis will be conducted. Characteristics of men who attended mass screening clinics were determined, including how many were first time participants. An assessment is underway of how those men with abnormal results made decisions whether or not to follow-up with their health care provider following notification of abnormal test results. This included telephone surveys to determine the men's understanding of their screening results, and determine if they consulted a health care provider about follow-up.

This presentation will demonstrate how faculty can create opportunities for research that also provide a service. Through this project, nurse practitioner students were given the chance to participate in community based research.

*This study is funded by a grant from the United States Department of Defense. Research and views represented here are those of the principal investigator's work for this study and do not represent views of the United States Department of Defense.*

## POSTER ABSTRACT

**School of Public Health Minority Health Conference  
University of North Carolina, Chapel Hill, N.C. February 16, 2001**

### **FOLLOW-UP OF MEN WHO PARTICIPATE IN FREE PROSTATE CANCER SCREENING: WHO GETS SCREENED AND WHY**

Marva Price, DrPH, MPH, RN, FNP  
Duke University School of Nursing

**Introduction:** Prostate cancer continues to rise in the United States at a faster rate for African American men than for White men. A prostate screening tracking system determined who attends free mass screening clinics, and assesses systematic follow-up of abnormal prostate specific antigen tests and digital rectal examinations. Telephone interviews were conducted to determine subjects understanding of their abnormal results and their follow-up. Also included were community-based focus groups to ascertain African American men's concerns and beliefs about prostate cancer screening and prostate cancer.

**Methods:** A survey was administered to 983 subjects in 1998 and 1999 to determine characteristics of men who seek free screening. In addition, 58 African American men who were non-participants in the screening were recruited into six focus groups. They were interviewed about their concerns and beliefs about prostate cancer screening and cancer.

**Results:** African American men were slightly less likely to attend mass screening clinics when compared with white men. Men who participated in mass screening were more likely to have attended college or have graduated from college, and were employed in upper levels.

**Conclusion:** In this urban sample, educated African American men 40 years and older were nearly as likely as White men to participate in mass prostate cancer screening. Factors that motivated and inhibited screening were determined.

**Keywords:** prostate cancer, mass screening, African American males

*This study is funded by a grant from the United States Department of Defense. Research and views represented here are those of the principal investigator's work for this study and do not represent views of the United States Department of Defense.*

**ABSTRACT: AMERICAN PUBLIC HEALTH ASSOCIATION,  
BOSTON, M.A. NOVEMBER 2000**

ID# 13840 Password: 439862

Name: Marva Price, DrPH, MPH, RN (FNP)

Box 3322 DUMC Durham, NC 27710

Duke University Medical Center

Duke University School of Nursing

**Free Community Prostate Cancer Screening: Who Attends And Why?**

Prostate cancer continues to rise in the United States at a faster rate for African American men than for White men, for reasons that are not clearly understood. The ultimate goal of this free screening service, provided by a major academic medical center, is to increase the number of men, particularly African American men, who seek prostate cancer screening, including the Prostate Specific Antigen Test (PSA) and Digital Rectal Examination (DRE), and accept follow-up services. The faculty outcome for this session will be to discuss a prostate cancer screening tracking system that provides systematic follow-up for men who attend annual mass screening clinics in an urban community.

This study of 700+ men analyzed how men with abnormal results made decisions to - or not to follow-up following notification of abnormal test results. Community based focus groups were used to ascertain African American mens' concerns about prostate cancer screening. Telephone follow-up was conducted for men with abnormal screening results to determine their understanding of their screening results, and if they consulted a health care provider for follow-up.

At the Conclusion of this session, participants will be able to:

<OL>

<LI>

Identify characteristics of men who attend mass screening clinics.

<LI>

Determine motivating factors for acceptance of mass screening for prostate cancer detection.

<LI>

Discuss attitudes and concerns that African American men have about prostate cancer screening.

<LI>

Identify factors that determine follow-up of abnormal results.

</LI>

</OL>

*This study is funded by a grant from the United States Department of Defense. Research and views represented here are those of the principal investigator's work for this study and do not represent views of the United States Department of Defense.*



**ABSTRACT: NATIONAL BLACK NURSES ASSOCIATION CONVENTION,  
WASHINGTON, D.C. AUGUST 2000**

Name: Marva Price, DrPH, MPH, RN (FNP)  
Box 3322 DUMC Durham, NC 27710  
Duke University Medical Center  
Duke University School of Nursing

**Free Community Prostate Cancer Screening: Who Attends And Why?**

Prostate cancer continues to rise in the United States at a faster rate for African American men than for White men, for reasons that are not clearly understood. The ultimate goal of this free screening service, provided by a major academic medical center, is to increase the number of men, particularly African American men, who seek prostate cancer screening, including the Prostate Specific Antigen Test (PSA) and Digital Rectal Examination (DRE), and accept follow-up services. The faculty outcome for this session will be to discuss a prostate cancer screening tracking system that provides systematic follow-up for men who attend annual mass screening clinics in an urban community.

This study of 700+ men analyzed how men with abnormal results made decisions to - or not to follow-up following notification of abnormal test results. Community based focus groups were used to ascertain African American mens' concerns about prostate cancer screening. Telephone follow-up was conducted for men with abnormal screening results to determine their understanding of their screening results, and if they consulted a health care provider for follow-up.

At the Conclusion of this session, participants will be able to:

Identify characteristics of men who attend mass screening clinics.

Determine motivating factors for acceptance of mass screening for prostate cancer detection.

Discuss attitudes and concerns that African American men have about prostate cancer screening.

Identify factors that determine follow-up of abnormal results.

*This study is funded by a grant from the United States Department of Defense. Research and views represented here are those of the principal investigator's work for this study and do not represent views of the United States Department of Defense.*

Appendix N: Meeting Podium/Poster Abstract  
**ABSTRACT: 11<sup>TH</sup> INTERNATIONAL CONFERENCE ON CANCER NURSING OSLO,  
NORWAY  
JULY 2000**

This presentation will describe how a faculty researcher in cancer nursing developed a tracking system for an annual free community prostate screening program.

Prostate cancer continues to rise in the United States and at a faster rate for African American men than for White men, for reasons that are not clearly understood. This project developed a prostate screening tracking system to provide systematic follow-up for all men with abnormal PSA's and DRE's who attended annual mass screening clinics in an urban setting. Further, factors are being determined that predict which men might seek prostate cancer test screening. The ultimate goal is to increase the number of men, regardless of ethnicity, who seek prostate cancer screening, including both the Prostate Specific Antigen Test (PSA) and Digital Rectal Examination (DRE), and accept follow-up services.

The project organized screening data on over 700 men who received free screening in 1998 and 1999. Data was collected from questionnaires and telephone interviews are underway. Characteristics of men who attend mass screening clinics will be determined, including how many are first time participants. An assessment is underway on how those men with abnormal results make decisions to - or not to follow-up with their health care provider following notification of abnormal test results. This includes community based focus groups to ascertain men's concerns about prostate cancer screening, and telephone follow-up of men who were screened to determine their understanding of their screening results, and determine if they consulted a health care provider and made the necessary follow-up visits.

**Marva Mizell Price, DrPH, MPH, RN**  
**Duke University School of Nursing**  
**Box 3322 DUMC**  
**Durham, N.C. 27710 USA**

*This study is funded by a grant from the United States Department of Defense. Research and views represented here are those of the principal investigator's work for this study and do not represent views of the United States Department of Defense.*



DEPARTMENT OF THE ARMY  
US ARMY MEDICAL RESEARCH AND MATERIEL COMMAND  
504 SCOTT STREET  
FORT DETRICK, MARYLAND 21702-5012

REPLY TO  
ATTENTION OF:

MCMR-RMI-S (70-1y)

20 Dec 02

MEMORANDUM FOR Administrator, Defense Technical Information  
Center (DTIC-OCA), 8725 John J. Kingman Road, Fort Belvoir,  
VA 22060-6218


SUBJECT: Request Change in Distribution Statement

1. The U.S. Army Medical Research and Materiel Command has reexamined the need for the limitation assigned to technical reports written for Grant DAMD17-00-1-0015 and Military Interdepartmental Purchase Request 5MCVEM6785. Request the limited distribution statement for Accession Numbers listed below be changed to "approved for public release; distribution unlimited." These reports should be released to the National Technical Information Service.

ADB282137  
ADB283906

2. Point of contact for this request is Ms. Judy Pawlus at DSN 343-7322 or by e-mail at judy.pawlus@det.amedd.army.mil.

FOR THE COMMANDER:

  
PHYLLIS M. RINEHART  
Deputy Chief of Staff for  
Information Management